Development of a framework to improve rehabilitation and health outcome in major trauma patients and trauma systems

Submitted in partial fulfilment of the requirements of the Degree of Doctor of Philosophy

Karen Hoffman

Blizard Institute, Centre for Trauma Sciences,

Queen Mary University of London, Royal London Hospital

London

Statement of originality

I, Karen Hoffman, confirm that the research included within this thesis is my own work or that where it has been carried out in collaboration with, or supported by others, that this is duly acknowledged below and my contribution indicated. Previously published material is also acknowledged below.

I attest that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge break any UK law, infringe any third party's copyright or other Intellectual Property Right, or contain any confidential material.

I accept that the College has the right to use plagiarism detection software to check the electronic version of the thesis.

I confirm that this thesis has not been previously submitted for the award of a degree by this or any other university.

Signature:
Date:

ABSTRACT

Rehabilitation outcomes are an important measurement of trauma system effectiveness. However, currently there is no clinically applicable trauma rehabilitation score or framework available to evaluate health and rehabilitation needs after trauma.

The World report on Disability (2011) recommended the application of the World Health Organisation International Classification of Function, Disability and Health (ICF) as a framework for all aspects of rehabilitation. A standardised language, based on coded categories would aid in international efforts to evaluate health and disability globally. The ICF framework has not been applied in trauma rehabilitation or trauma systems to date.

The objectives were to investigate rehabilitation needs of trauma patients and evaluate to what extent the ICF can be used as a framework to capture and assess health and rehabilitation outcome of patients following traumatic injuries.

Two cohort studies with 103 and 308 patients respectively demonstrated the utility of the Rehabilitation Complexity Scale (RCS) in an acute trauma setting. The RCS outperformed other acute measures and rehabilitation complexity correlated with length of stay and discharge destination.

A systematic review of 34 articles confirmed that outcome measures frequently used in trauma outcome studies represent only six percent of health concepts contained in the ICF.
A quantitative international on-line questionnaire with expert clinicians working in trauma (n=217), identified 121 ICF categories pertinent to rehabilitation and health outcome of trauma patients. Qualitative patient interviews (n=32) identified nearly double the amount of ICF categories (n=234) compared to clinicians. Combined analysis of qualitative and quantitative data presents 109 ICF categories important for rehabilitation and health outcome assessment of trauma patients, using the ICF as a framework.

This thesis describes the need for improved outcome evaluation of trauma patients. It demonstrates the acceptability of the ICF language and framework amongst clinicians and suggests the application of the ICF as a framework for trauma service delivery and outcome assessment.

I dedicate this to my family.

To my loving mom, dad and two beautiful sisters

ACKNOWLEDGEMENTS

I would like to thank a number of people whom has supported, encouraged and cared for me over the past few years as I conducted this research.

First and foremost I would like to express my deepest gratitude to Professor Karim Brohi for believing in me and my ability to conduct and to complete this research. Thank you for your patience, supervision and encouragement. The past few years have been filled with many exciting challenges and opportunities. I have learnt so much from you and continue to be inspired by your commitment to research and desire to improve all outcomes after trauma. Thanks to Diane Playford for the time you took to guide my thoughts and ideas in the right direction whilst being pragmatic about things.

I have so many friends to thank. My occupational therapy friends, many of whom I have known for a very long time – Andrea, Mary, Gerard, Fiona, Tess, Sarah, Wendy, Sue, Sandy, Marcus, Austin and Deanna. Thank you for support both professionally and in friendship.

Very special thanks to my multiple South African friends that ensured that I maintain a balance between work and pleasure and encouraged me every step of the way. Yvette, Geoff, Jason, Keata, Sharon, Jon, Nicole and Anton, I am in debt to you.

Tina and Mando – your encouragement, reassurance and inspiration from both near and far has made this possible. Stephane, your motivation and patients throughout is much appreciated.

Thank you to all the team members in the Trauma Unit, research fellows, research assistants and Aysha.

Thank you to my very dear colleagues Anita and Elaine, for your physical and emotional support and for doing this with me every step of the way.

Finally, I would like to thank my family for believing in me and your day to day encouragement. Thanks to my mom, dad, Shereen, Tertia and René for your loving support. You are with me every day even if you are 10 000 miles away.

PEER REVIEWED PUBLICATIONS AND PRESENTATIONS RELATED TO THIS THESIS

PUBLICATIONS

Hoffman K, West A, Nott P, Cole E, Playford D, Liu C, Brohi K. Measuring acute rehabilitation needs in trauma: Preliminary evaluation of the Rehabilitation Complexity Scale. Injury 2013; 44(1): 104-9

Hoffman K, Cole E, Playford ED, Grill E, Soberg HL, Brohi K. Health Outcome after Major Trauma: What Are We Measuring? PLoS One 2014; 9(7):e103082.

Hoffman K, Cole E, Playford ED, Grill E, Soberg HL, Brohi K. Towards a Framework for Health Outcome Assessment in Trauma Care: Patients' and Professionals' Perspectives (Submitted 2014)

PUBLICATIONS RELEVANT TO THIS THESIS

Khan F, Amatya B, Hoffman K. Systematic review of multidisciplinary rehabilitation in patients with multiple trauma. Br J Surg. 2012;99 Suppl 1:88-96.

CONFERENCE PRESENTATIONS

European Federation for Research in Rehabilitation (EFRR) – Lake Garda, Italy, May 2011
Measuring Acute Rehabilitation Needs in Trauma: Preliminary Evaluation of the Rehabilitation Complexity Scale

London Trauma Conference – London, UK, June 2011
Can we Measure Rehabilitation Needs after Trauma?

College of Occupational Therapists (COT) Annual Conference – Brighton, UK, July 2011
Measuring Acute Rehabilitation Needs in Trauma: Preliminary Evaluation of the Rehabilitation Complexity Scale

Australasian Trauma Society (ATS) and Trauma Association of Canada (TAC) – Whistler, April 2013
Patient perception of recovery following severe trauma

London Trauma Conference – London, UK –December 2013

Trauma outcomes and the International Classification of Function (ICF)

Society for Research in Rehabilitation (SRR) – London, UK, February 2014

Evaluating rehabilitation needs: Utility of UK ROC instruments in trauma patients

United Kingdom Critical Care Research Forum (UKCCRF) – Cardiff, UK, June 2014

Survival is not enough -patient perception of outcome

British Society for Rehabilitation Medicine (BSRM) – Bristol, UK, October 2014

Health and rehabilitation needs after traumatic injury: an international expert perspective based on the ICF

Table of contents

LIST OF TABLES

LIST OF FIGURES

ABBREVIATIONS

BDI	Beck's Depression Inventory
BI	Barthel Index
CES-D	Centre for Epidemiologic Studies Depression Scale
CAPS	Clinician-Administered PTSD Scale (German version)
CMG	Case Mix Group
DALY	Disability-adjusted life years
DES	Dissociative Experience Scale
DRG	Diagnostic related group
DTS	Davidson Trauma Scale
EC	Elaine Cole
EuroQol	European Quality of Life Scale
FCI	Functional Capacity Index
FAQ	Functional Activities Questionnaire
FIM	Functional Independence Measure
FIM	Modified Functional Independence Measure
GARS	Groningen Activity Restriction Score
GHQ	General Health Questionnaire
GOS	Glasgow Outcome Scale
GOSE	Glasgow Outcome Scale Extended
GRADE	Grading quality of evidence and strength of recommendations
HADS	Hospital Anxiety and Depression Scale
HASPOC	Hannover Score for Polytrauma Outcome
HCP	Health care professional
HF-ICF- 60	Health and Functioning ICF-60
HRQOL	Health related quality of life
HRG	Healthcare Resource Groups
HUI 3	Health Utilities Index III
ICF	International Classification of Function, Disability and Health
ICF-CS	ICF Core Set
ICIDH	International Classification of Impairment, Disability and Handicap
ICD-10	International Statistical Classification of Diseases and Related Health Problems- tenth version

IES-R	Impact of Events Scale-Revised
IQCODE-SF	Informant Questionnaire of Cognitive Decline in the Elderly-Short Form
IPAQ	Impact on Participation and Autonomy Questionnaire
IRT	Item Response Theory
ISS	Injury Severity Score
JCQ	Karasek's 31-item Job Content Questionnaire
Katz ADL	Katz Index of Independence in Activities of Daily Living
KH	Karen Hoffman
LOS	Length of stay
MDT	Multi-Disciplinary Team
MFA	Musculoskeletal Function Assessment
MTC	Major Trauma Centre
NICE	National Institute for Health and Care Excellence
NHS	National Health Service
PCL	Post-Traumatic Stress Disorder Checklist
PM-PAC	Participation Measure for Post-Acute Care
PRF	Patient Report Forms
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses process
PROM	Patient Reported Outcome Measure
PROMIS	Patient-Reported Outcome Measurement Information System
PTSD	Post-Traumatic Stress Disorder
PTSS-10	Post Traumatic Symptom Scale
QALY	Quality Adjusted Life Year
QOL	Quality of life
RCS-E	Rehabilitation Complexity Scale - Extended
RCSV2	Rehabilitation Complexity Scale version 2
RCT	Randomised control trials
RLH	Royal London Hospital
SF-36	Medical Outcome Study Short Form Health Survey
SIP	Sickness Impact Profile
SSQ	Social Support Questionnaire
TARN	Trauma Audit Research Network
TOP	Trauma Outcomes Profile
TOU	Trauma Outcomes Unit

TTO	Time Trade-off
TU	Trauma Unit
UK	United Kingdom
VAS	Visual Analogue Scale
VSTR	Victorian State Trauma Registry
WHO	World Health Organisation
WHODAS ll	World Health Organisation Disability Assessment Schedule version 2
YLD	Years Lived with Disability
YLL	Years of Life Lost

Chapter 1: INTRODUCTION

1.1 Trauma epidemiology

Major trauma can be described as serious injury, often involving multiple body regions with death or disability as a possible consequence (1). Others describe major trauma as 'injury to the brain in addition to other body parts or systems resulting in physical, cognitive, psychological, or psychosocial impairments and functional disability which could include impairments in cognition, physical, psychological or other psychosocial aspects' (2). Major trauma is thus more than an isolated injury such as a spinal cord injury or a traumatic brain injury and may involve many body systems and affect different body parts as well as the overall health of an individual. The Injury Severity Score (ISS) (3) is used to classify the severity of trauma and a score of >15 is defined as major trauma. The maximum score is 75 which is an un-survivable injury.

The World Health Organisation (WHO) estimates that road traffic accidents account for more than 1.23 million deaths each year with 20 to 50 million people suffering non-fatal injuries. In England there are an estimated 20 000 trauma cases each year with an additional 28,000 cases, not necessarily severe enough to be classified as major trauma (1). Of these, approximately 5400 people would die (1). The initial treatment costs for the NHS are projected at £0.3 to £0.4 billion per annum with subsequent economic cost mounting to approximately £3.3 billion although the exact cost of rehabilitation, home care and informal carer cost are unknown (1). Moreover, societal cost and loss of productivity due to disability could be more costly than initial medical care costs (4, 5). The true long term economic impact could thus be grossly underestimated as major trauma occurs in younger people who will live longer with considerable ill health and loss of income (6, 7).

1.2 Outcomes after trauma

Each year, 45 million people worldwide survive traumatic injuries many of whom are left with moderate to severe disability and potential long term health problems (8). The consequences are complex, heterogeneous and multi-faceted and are often undermined or unrecognised. Trauma can have significant psychological and psychosocial impacts on the individual and their family; some problems are more obvious and recognised than others. However, the most commonly quoted outcome remains mortality (9-15). Mortality is a concrete outcome and only represents a small proportion of trauma patients. It does not capture or analyse the quality of survival for the rest of the trauma population (16, 17).

A focus on mortality detracts attention from other important governance and research priorities which should focus on the impact that trauma has on survivors and the burden of morbidity (17).

The need for improving outcome of patients with traumatic injuries in the United Kingdom (UK) was highlighted in 'Trauma: Who cares' published in 2007 (18). This document was published by the National Confidential Enquiry into Patient Outcome and Death (15). The overall purpose of the recommendations was to reduce mortality and unnecessary morbidity and thus improve the care of the severely injured patient. The document also recommended the need for a nationally coordinated systematic audit process and improved organisation of trauma services in the UK. As a result trauma networks are being set up in the UK to enable improvements in pre-hospital and acute care (19). However, trauma system effectiveness continues to be measured by mortality (10) and in the UK, the evaluation of medium and long term health outcome and quality of survival following traumatic injuries remains absent (17, 20, 21).

Mortality measures, although important, provide health care providers incomplete and insensitive information about overall health outcome after trauma (22). Information about health service needs after trauma, access to health services, service use, rehabilitation and the cost related to this is not currently captured in the UK (23). The cost of acute care is largely determined by length of stay (LOS). Factors such as infections increases the cost and duration of acute admission (24). However, LOS is not currently a trauma system performance measure (23). Several publications have highlighted the need to develop processes to reduce length of stay in order to reduce the cost of acute trauma care (23-26). In recognition of this, 'trauma and injuries' have been included in the National Health Service (NHS) Outcome Framework in England, Domain 3 (helping people recover from episodes of ill health or following injury) as an area for service improvement (17). It is anticipated that initiatives will produce more detailed information, collected through governance, audit and research to improve our understanding of the recovery trajectory and health consequences for trauma survivors (27).

Despite the lack of routine measurement of morbidity there are numerous research publications describing the physical, emotional and psychological consequences of trauma. Physical disabilities due to amputation (28-31), brain injuries (32), fractures (33) or spinal cord injuries (34-36) are common after trauma and often associated with complications

such as pain, anxiety and depression. Many patients experience pain for long periods after their injury (37, 38) some of which can lead to emotional dysfunction (37, 39), phantom limb pain (40, 41) and in extreme cases chronic pain (42, 43). Some authors have also suggested an association between pain, post-traumatic stress disorder (PTSD) (40, 44) and post-concussion syndrome (45). Whilst it is well known that head injuries have a significant impact on psychosocial and neuropsychological outcome (46, 47), functioning is equally affected for non-head injury patients (48), even those with minor injuries (49).

The incidence of psychological symptoms, particularly the rate of PTSD varies widely in the literature. It is estimated that between 15% and 60% of patients will develop PTSD or post-traumatic stress type symptoms (50-55). PTSD related symptoms can compound physical burden due to sleep deprivation and physiological reactions to reminders (56-58). A proportion of patients will also develop other psychological problems such as anxiety or depression. Again, the literature pertaining to the timeframe for the resolution of these impairments varies (54, 59, 60). There is limited evidence examining the relationship between major trauma and cognition. A few authors extrapolated cognitive implications from individual cognitive questions contained in outcome measures (61, 62). Some studies report that up to 65% of patients have cognitive complaints (63) where others describe patient reported cognitive impairments which include memory, attention concentration and thinking (64). This combination of physical, emotional and cognitive consequences directly impacts on independence in every day functional tasks and other activities related to family and social commitments (31). Regardless of the recognised impact of these problems, psychosocial factors are often neglected despite the influence this can have on duration of recovery (65, 66).

In addition to physical and emotional problems, there is an enormous financial burden on individuals due to loss of employment or long periods away from work. Trauma survivors are predominantly young and represent the largest proportion of working age adults living with long term disabilities (8, 67, 68). Many people struggle to return to work after injury which can take up to 12 months (69). This unrecognised and misjudged length of long term recovery puts extra pressure on the health and social care system as well as personal, family and societal burden (70).

In addition to the problems faced by survivors, several other factors impact on recovery. People at risk of worse outcomes are females, older adults, blue collar workers (manual

labour) and less educated individuals (62, 63, 71-74). Injury location, injury severity and mechanism of injury also effects outcome (75, 76). Recently, unresolved compensation claims also showed to influence overall outcome after trauma (77, 78). Whilst these problems and factors have a great impact on outcome and recovery, they are not routinely measured or considered in trauma care or trauma system performance. The lack of minimum service standards in terms of what should be measured or a framework for outcome evaluation limits our understanding of the precise characteristics of health outcome. Consequently, the holistic range of factors impacting on the rate and extent of recovery remain vague.

1.3 Defining health and rehabilitation terminology

In order to review the current management in trauma rehabilitation, it is necessary to understand how the current models of disability and rehabilitation are interpreted and used. Within routine clinical practice, the terms disability, function and health are often confused or used interchangeably. It is important to differentiate between these terms and also to understand and use them correctly to ensure accurate assessment and understanding of problems faced by trauma survivors. Worldwide, health status is defined or distinguished with diagnostic codes such as the International Statistical Classification of Diseases and Related Health Problems- tenth version (ICD-10)(79). The ICD-10 codes are used to classify disease, disorders and other causes of death. They are often used to determine the cost of medical procedures, disease severity and cost of health care services. However, they do not provide information of the impact of the disease or diagnosis on function and health outcome (80, 81). Two people with the same diagnosis may have very different levels of function depending on the everyday activities that they need to perform and how they perform them.

It is essential to understand the *contemporary meaning of health* before efforts are made to assess, maintain or improve health outcomes. Concepts of disability and health have developed over time with advances in medicine. As early as 1947 the WHO defined *health* as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (82). Despite this all-inclusive definition, the accurate measurement of health as a complex interaction between social aspects as well as physical and mental function has taken years to develop. Over the past decades the understanding of disease, disability and dysfunction changed from a negative focus to a more positive focus of health. This change in understanding is attributed to advances in medical care which led to a shift

in focus from endemic disease to chronic disease and recognition of important consequences beyond mortality. Disability was a negative term used to describe dysfunction although there was no specific standard to assess a person's function or deviation away from it. In an effort to better describe and define health and disability, new models of disability began to evolve in the 1950s (83, 84). It was recognised that morbidity needs to be captured and the impact of survival on autonomy and daily life (83).

There is also much debate around the meaning of *function*. The term *functional status* is more than just performing activities. It is the degree to which a person is able to perform socially appropriate roles free from limitations related to physical or mental impairments in an appropriate context (85). *Function* is an integral part of health and can be visualised along a continuum where disability is at the one end and functioning at the other end. Some might argue that the terms function and health could be used interchangeably. However, there is no specific model or theory to describe function although it is an integral component in health frameworks and models of disability. Function should thus be regarded as a component of health, measuring the effects of disease (85). The correct understanding and application of concepts, such as impairment, disability, function and dependency is vital to ensure appropriate selection of outcome measures and subsequently accurate evaluation of the impact of disease or disorders on overall health outcome.

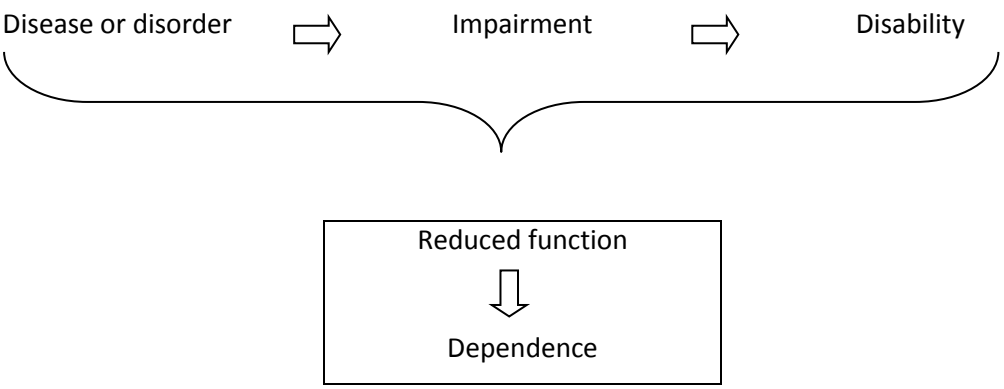
Rehabilitation has traditionally been underpinned by the medical model from which much of the terminology in use are derived (86). The medical model, otherwise known as the curative model assumes an optimal level of functioning which humans should aspire to. On this basis medical and rehabilitation professionals reinforce that the body must be 'fixed' to fit the environment, emphasising cure and ignoring sociocultural prejudices and patient preferences (86, 87). Within this model, *impairment* is a direct result of a disease or a disorder. Changes seen in an individual after traumatic injury could be *impairments* in body structures or body functions which can be anatomical loss, physiological or psychological functioning (85). Thus *impairments* refer to problematic biological functions and rehabilitation professionals work to restore the impairments. There is limited consideration of the impact of the environment or society on the individuals' problems and the person needs to adapt to the society.

In contrast, *disability* refers to restrictions in functional activities. Disability is concerned with activities performed by a person and any restriction or lack of ability to carry out the

activity in a normal range. Disability is not an issue of ill health and may not require medical attention (86) but refers to the barriers experienced by individuals such as access to buildings due to an amputation. Previous level of function cannot be restored or cured due to a permanent or acquired condition. Thus, individuals experience some sort of dysfunction deviating from 'normal' or 'expected' performance.

Impairments and disability often leads to *dependence* which is defined as 'a state where an individual relies on others for assistance to meet their needs'(85) (Figure 1.1). These concepts and their meaning need to be considered during outcome measure selection. A measure may purport to evaluate disability in terms of activity performance, but actually evaluates impairments, such as pain of discomfort (88).

Figure1.1 Linear consequences of disease

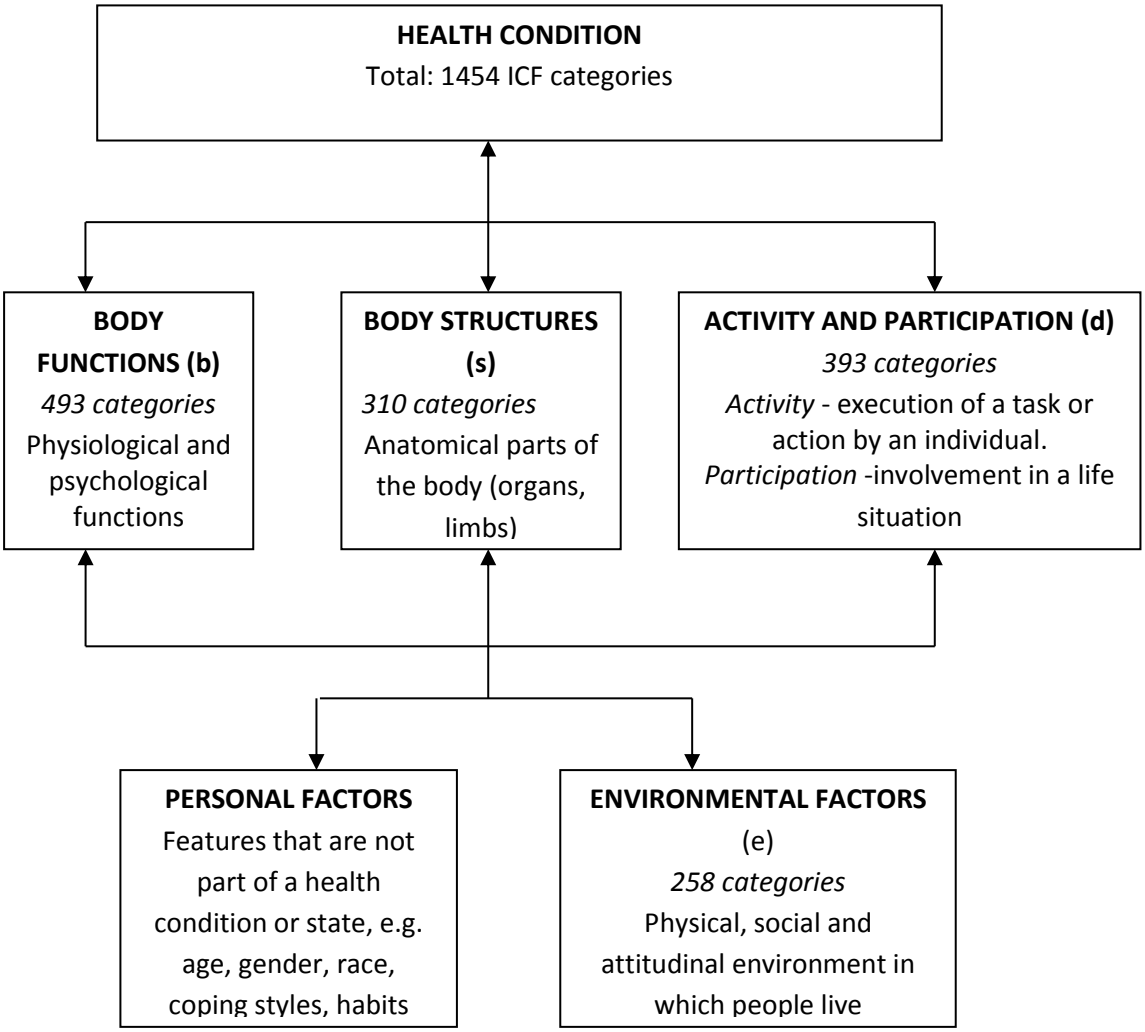


The curative model lost some of its relevance after the Second World War as infectious diseases were progressively disappearing and chronic disease and incapacities became more apparent (89). The 'normative nature' of the curative/medical approach was challenged and more person-centred 'social' models of disability emerged. These models described 'externally imposed restrictions' as the cause of disability and social isolation. These models also considered the consequences of health problems rather than their causes, and identified the obstacles that prevented full social participation (86, 90). The Social Model of Disability (91) and Nagi's Functional Limitations Model (92), sometimes referred to as the Disablement Model (93) shifted the focus from physical consequences of disease to a more dynamic process which considers the social context and functional consequences. The Social Model of Disability argued that society is the main contributing

factor in disabling people due to negative attitudes, exclusion by society and systemic barrier which needs to be recognised and addressed to reduce disability. On the other hand, the Functional Limitation Model differentiated between impairment, disability and function. Impairment related to an abnormality or loss at organ, tissue or body systems level, where function limitations referred to performance restrictions of a specific task. Disability was limitations in performing expected task or socially appropriate roles within a physical environment or appropriate sociocultural context (94). This model was the model of choice for the Institute of Medicine (IOM) (95) in the United States of America until recently (96). These key models has influenced the current understanding of function, disability and health and influenced rehabilitation practice. However, these disability models did not develop sequentially but rather co-existed and overlapped limiting a true shift to client centred rehabilitation.

More recently the WHO International Classification of Impairment, Disability and Handicap (ICIDH) was developed and became the first internationally known framework to classify the consequences of diseases (97). It defined terms of impairment, disability and handicap with a linear interaction which conceptually linked concepts together and was translated into 13 languages. However, the ICIDH received criticism for the oversimplification of disability caused by impairment and the failure to recognise social and psychological factors which can influence disability (83, 98). As a result, a revised version was published in 2001, the International Classification of Function, Disability and Health (ICF) which was endorsed by the WHO (99). It moves away from disability as consequences of disease to focus on components of health with a non-linear interaction between contextual factors and function (85). The ICF use a coded classification system, similar to the structure of the ICD-10. It provides clinicians and health care professionals with a standardised language to describe functioning and contextual factors impacting on participation in life events (Figure 1.2) In the last decade the application and use of the ICF as a bio-psychosocial model has increased significantly in rehabilitation research (100-102) and its application in social and health care systems (103-107).

Figure 1.2 WHO International Classification of Function, Disability and Health (ICF)



The ICF intentionally moves away from the negative connotation of illness, sickness and disease to positive health. It aims to integrate the medical and social model in order to be more patient centred and describes components and consequences of health in relation to contextual factors (89). The ICF and its application in trauma and rehabilitation are discussed in more detail in section 1.5 of this chapter.

Despite the developments in disability models, concepts of health continue to be debated. Some critics argue that the WHO definition of health is unhelpful, as the concept of 'wellbeing' is part of 'health' and it is not just about an absolute absence of disease or disability (108, 109). Other health professionals and health services continue to have a reductionist view of health and continue to treat *components* of a problem, rather than have a holistic view of an individual (110-113).

The acute nature of trauma lends itself to the application of the Medical Model. This model assumes that disease leads to changes in the body's structure or body functions which can be repaired or replaced. Trauma systems place a strong focus on preventing body function failures such as shock or bleeding (114) or repairing body structures which were damaged as a result of the injury (115). Trauma as a disease, based on a Medical Model often focuses on mortality which limits consideration or evaluation of other important health outcomes. Moreover, certain measures will only focus on evaluating a single component such as muscle strength and pain (impairments) or walking (function). Patients may experience ill health which is not necessarily detected by biochemical indicators or the subjective understanding of dysfunction (116). Injury results in a chain of reactions that not only affects the integrity and function of a body part but the performance of an individual and their involvement in the community (117). A persons functioning may be influenced by several factors such as pain, medication, the environment, fatigue or anxiety. These factors and their impact need to be considered when choosing instruments or designing frameworks to measure health outcome (20, 50). Moreover, outcome data needs to be collected over several time periods to enable through analysis of the impact of injury on long term health outcome (118).

In addition to understanding the difference in the concepts discussed previously there remains another important concept; that *of quality of life (QOL)* or *health related quality of life (HRQL).* In general, QOL is defined as the grade of goodness of life and HRQOL the grade of goodness of life in relation to aspects of life affected by health (85). The World Health Organisation defines QOL as 'an individual's perception of their position in life in the

context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns' (119). Quality of life data is collected for a variety reasons. Health care organisations use QOL data to calculate quality adjusted life years (QALY) to justify cost effectiveness of treatments. The National Institute for Health and Care Excellence (NICE) use QALYs to determine the cost-benefit analysis for health technology such as drug treatment (120, 121). In population health disability-adjusted life years (DALYs) are calculated using QOL measures. This is used to calculate the impact of disease and injury in terms of years lived with disability (YLD) in non-fatal diseases or injures and years of life lost (YLL) (122). Policy makers use the DALY methodology to evaluate effectiveness and cost effectiveness and set priorities for prevention strategies. This is of particular relevance in trauma care as is used to evaluate the of burden of injuries as well as developing public health strategies to prevent road traffic accidents, cycling injuries and other un-intentional injuries (122-125). Internationally, the European Quality of Life Scale (EuroQol) (126) is used the most frequently and consistently in population health studies and trauma research (127). Two other generic QOL measures frequently used in trauma and brain injury research and clinical practice are the Medical Outcome Study Short Form Health Survey (SF-36) (128) and the Glasgow Outcome Scale (GOS) (63, 74, 129, 130).

More recently health care services recognised the value of patient feedback and patient experience in addition to the evaluation of system performance in terms of clinical and process indicators (85). Patient reported outcome measures (PROMs), often in the form of QOL data are used to capture patient experience and patient perceived outcomes (131-133) to improve services (134). Several condition-specific PROMs have been developed, in particular for musculoskeletal conditions (135-137) although there is currently no trauma specific PROM nationally or internationally.

As the understanding of disease, disability and health has changed over time, so did the measurement of these concepts. It is essential to select appropriate instruments which are developed within a modern framework of health and reflect the current understanding of health concepts. This will ensure accurate evaluation of health outcome which continues to be one of the most important outcomes of health care (85).

1.4 Trauma systems and long term outcome evaluation

Trauma systems and the use of outcome measures within these

Much effort has been made in the last 30 years to investigate clinical procedures and processes to improve survival rates of trauma patients (138-141). Best practice for both pre-hospital and in-hospital care of severely injured patients has been a topic of debate (142). Trauma systems were developed in the late 1970 in California after it was demonstrated that patients had a lower risk of preventable death if taken to a hospital where physicians have specialist skills in dealing with major injuries (143, 144).

Regional trauma systems aim to improve outcomes by matching patients' needs to resources and expertise in a time-dependent and cost-effective manner. This involves a hub and spoke model where major trauma centres (MTCs) have additional resources and expertise that are linked to, and support smaller trauma units (TUs) within a specific geographical area (145). Ambulance triage systems are used to evaluate the severity of injury to ensure patients get transported to the most appropriate facility in a timely fashion. Population-based evidence supports a 15 to 20% improved survival rate among seriously injured patients with trauma system implementation. However, further studies are required to determine whether trauma systems improve the outcome of all injured patients, not just high-risk subsets of the population (146-148).

Healthcare services, systems and policies aim to maintain or improve the health of people (149). They monitor and analyse performance and processes using information collected on databases or registries (116). Similar approached are used in trauma. Trauma registries have a wealth of information related to very specific outcomes albeit health outcomes (150). Audit tools, audit filters (151) and core data sets have been recommended (152, 153) as part of quality measures for trauma service delivery (140) and trauma systems (154). In an effort to move away from the negative outcome of injuries such as mortality, some trauma registries collect post discharge outcome data (9). Several studies summarise measures used in trauma registries (9, 17) although this is not routine practice. The majority of measures relate to quality of life and function and include EuroQol, SF36, the Functional Independence Measure (FIM) (155) and the Glasgow Outcome Scale (GOS) (129, 154). A recent study recommends the use of the Glasgow Outcome Scale Extended (GOSE) (156, 157) rather than the FIM as it overcomes the ceiling effects of the FIM. The Victorian

State Trauma Registry (VSTR) in Australia is possibly the only trauma registry that have demonstrated the successfully implementation of cost effective population monitoring of QOL and functional outcome up to two years post injury using telephone interviews and a variety of measures (158).

In the UK, the Trauma Audit Research Network (TARN) is the trauma registry that collects and co-ordinates data collection on outcome after trauma nationally. The majority of the data collected relates to pre-hospital and acute care process and procedures. In order to be entered into the TARN registry, patients must have a length of hospital stay of ≥72 hours. Additionally there are injury-based restrictions, where patients with minor injuries such as a closed tibial fracture are excluded regardless of their length of stay (159). However there are four data points related to rehabilitation which must be completed as part of the minimum data set in order for trauma units and major trauma centres to receive funding in the form of a best practice tariff. These data points record the presence or absence of physical disability, cognitive/mood factors and psychosocial factors as a yes/no data field. There is thus no detailed information on the persons' actual rehabilitation needs, preferences or impairments limiting the overall understanding of rehabilitation requirements.

Outcome measures used in trauma research

The need for standardised outcome and performance measures which are collected longitudinally over the recovery trajectory and that are meaningful to patients, carers, clinicians and service providers has been emphasised (19, 154). However, there remains no consensus as to which measures are the most appropriate. Many of the outcome measures used traditionally were developed for chronic progressive diseases and are not specific to trauma (20). Their application is further limited by factors such as resource limitations in terms of cost, time and man power to ensure appropriate, complete data collection (9). Outcome measures need to collect information relevant to different stakeholders whom may have different priorities in terms of cost and quality of outcome (9).

Consensus opinion (160) and international guideline documents (161) previously recommended the use of the European Quality of Life Scale (EuroQol) (126), Glasgow Outcome Scale (GOS) (129) and the Health Utilities Mark III (HUI 3) (162) to measure injury-related disability and quality of life in follow-up studies. Even so, they are not widely used in outcome studies (20, 63, 163) or at consistent time points (16). Several systematic

reviews focused on measures used in trauma care (164), physiological and anatomical scoring systems (165), measures used for upper limb assessment (166) and quality of life measurement after trauma (167-169). The reviews did not recommend one instrument; rather, they supported the need for improved scale selection or development of a trauma outcome framework to capture all components related to health outcome (20).

The lack of implementation or consensus in relation to which measures to use at a trauma system level and in research limits comparison of outcome between patient populations due to the heterogeneity of data. Moreover, certain measures are used regardless of recognised ceiling effects, thus being unable to capture improvement in function. For example, functional measures such as the FIM are used in trauma studies (170, 171) and traumatic brain injury studies (172-174). However, the application is limited by a ceiling effect once a person leaves rehabilitation (175, 176). The FIM is also inadequate in terms of measuring the burden of injury such as return to work and participation in important life events.

The Functional Capacity Index (FCI) (177) remains one of the only instruments developed specifically for trauma populations but it has not been recommended for use in previous consensus papers (160) and lacks validity in predicting long term outcome (178). Thus, the application, validity and complexity of trauma specific instrument remain questionable. There is an urgent need for the development and application of measures to improve health outcome evaluation to evaluate patient perception of outcome and trauma system performance.

1.5 Rehabilitation needs after trauma

Definition of rehabilitation

As previously discussed in section 1.3, rehabilitation has traditionally been underpinned by the medical model with a curative approach ignoring patient preferences and societal impacts (86). The introduction of the ICF led to a shift from this practice and emphasised the patients' performance in the social context as part of the rehabilitation process (179). Moreover, it includes important environmental aspects such as support from family and friends, society and services which are important considerations in terms of participation priorities. Some authors refer to environmental factors as the 'scaffolding' that provides support for a person with disabilities (180). However, although the ICF includes personal

factors as part of the conceptual framework, it does not take into account temporal factors such as the past, present and future and how these impact on a persons' stage of life or illness (181, 182). Although personal factors as internal resources, and environmental factors as external resources can help the reconstruction of 'personhood' (183), the ICF continues to lack a classification system for personal factors to categorise personal strengths or assets (184).

Rehabilitation is instrumental in enabling people with limitations in functioning to remain in or return to their home or community, live independently, work and participate in education and civic life (185). Thus, rehabilitation has shifted from largely being a medical concern to a more complex process which involves a holistic view of a person whilst using specialists skills to improve the persons psychological, biological and social functioning (184). More so, it also includes the process of a person having to adjust and learn new knowledge to deal with their change in circumstances to restore autonomy in aspects of life that patients and families regard as important (184). It is thus important to engage patients in activities that are meaningful and important for them to ensure optimal recovery. Essentially, rehabilitation needs to be person centred rather than standardised and should be adapted to each individual's values and preferences (186). Despite the strong case for person centred rehabilitation there remains uncertainty amongst rehabilitation professionals if they are really empowering people to be autonomous in their rehabilitation.

For the purpose of this thesis rehabilitation will be defined as a complex intervention which requires education and problem-solving by both patients and health care professionals. It aims to optimise a patients' activity limitations to enable social participation and wellbeing whilst reducing the stress experienced by the family or carer (182). Regardless of the exact context of the rehabilitation service, the process usually involves four components; that of assessment, goal setting, intervention and evaluation (184). This process is known as the 'rehabilitation cycle' (101, 182).

Rehabilitation remains a key component in the process of recovery from injury and the focus may change over time. However, the recovery trajectory is poorly defined in trauma and there is a notion to describe 'therapy' rather than 'rehabilitation'. Rehabilitation, as a process, should be patient centred and usually involves a variety of therapists. Giving someone 'therapy' does not necessarily mean they are receiving rehabilitation. Similarly,

spending time in a rehabilitation unit does not mean the person is receiving rehabilitation (184). This particular issue is evident in trauma rehabilitation where it is suggested that rehabilitation is measured with a scale that captures how many different therapists are required rather than the amount and type of therapeutic input (159). Moreover, the limited rehabilitation prescriptions required for TARN de-personalises individual goals and priorities, removing the locus of control from the patient and giving it back to the system (187). There is thus an pressing need to improve patient centred rehabilitation in trauma to gain insight into patient priorities and outcomes.

Factors impacting on rehabilitation

As survival from injury increases, so does the need for rehabilitation and access to rehabilitation. However, many factors can impact on long term rehabilitation outcome which need to be considered. Patients could have the same injuries or injury severity but have very different rehabilitation needs and outcomes due to a variety of factors. These may include secondary complications such as deep vein thrombosis (188) (189), heterotopic ossification (190, 191) and frailty (192). Acute care interventions aim to reduce the prevalence of secondary complications in order to maximise the patients' potential of recovery. For example, some studies demonstrated the benefit of early mobilisation to reduce the formation of heterotopic ossification (193). However, patients do not always have access to early rehabilitation interventions (194). Many of these needs and factors are not currently captured in trauma care and their impact on outcome requires further attention.

Other factors impacting on rehabilitation are service related. These include resources such as staff, equipment, time frame of rehabilitation intervention and access to rehabilitation facilities (195). Environmental factors can also impact on rehabilitation and may include access to public and private buildings, equipment, policies and access to systems and services (196). Whilst all of these factors impact on long term outcome, I will focus on the importance of early access to rehabilitation and rehabilitation needs and complexity of patients as this has recently received much attention (197-200).

Timing of rehabilitation

The importance and benefit of early access to rehabilitation has increasingly been recognised. Conditions such as stroke and coronary heart disease reported fewer complications and better functional gains in patients who received early rehabilitation

interventions (201-206). Acute rehabilitation also helps to prevent the development of secondary complications and adverse effects of immobility (207, 208). In brain injury early rehabilitation was correlated with reduced disability, improved mobility, reduced acute length of stay (25) and improved cognitive levels at discharge (209). In critical care, ventilator days and hospital length of stay were reduced (200, 210). However studies do not describe the actual rehabilitation needs of patients or the dose (in time) or type of rehabilitation provided. A greater understanding of patient rehabilitation needs, and barriers and facilitators at a system level will enable effective service development and evaluation of trauma system efficiency and performance (211, 212). A study conducted nearly 20 years ago found that geriatric trauma patients receiving rehabilitation and coordinated care, had a significantly reduced length of stay compared to patients who did not receive rehabilitation or coordinated care (213). Surprisingly the authors of this study concluded that a reduction in length of stay is not an important outcome and attributed the findings to care coordination rather than rehabilitation. Twenty years later, reducing length of stay is regarded as a very important performance measure in the NHS (25, 26, 214) although the struggle to justify early rehabilitation continues (215, 216). Although these aspects have significant impact on patient outcome and trauma system performance, there are no guidelines on early trauma rehabilitation interventions or processes to reduce length of stay.

Complexity measurement and cost of rehabilitation

In the UK, funding agreements for payment of trauma care are currently governed by the NHS Standard Contract for Major Trauma Service (217) and the Department of Health (DH) guidance on Payment Results for Major Trauma (218). Both of these documents base tariff payments on ISS scores despite evidence that suggest other factors should be considered (219). The need for alternative cost models have been demonstrated in neurological rehabilitation in the UK (220) but have not yet been considered in trauma.

Fixed tariff models are used worldwide to establish cost and payment for treatment in healthcare systems (221). Diagnostic related groups (DRGs) or Healthcare Resource Groups (HRGs) were developed to measure and classify health care activity, taking into account the complexity of patients, based on their diagnosis, procedures performed and resources used. Each DRG or HRG has a fixed tariff (222). This model works well for specific medical interventions where standard medical or surgical procedures are more or less the same, however tariffs for rehabilitation are more complex (223). Stroke and brain injury

rehabilitation studies conducted in America demonstrated a negative impact on outcomes after the introduction of a prospective payment system (224-226). There is a complex relationship between patient and process factors in rehabilitation which needs consideration (227).

There are a limited amount of measures available to measure rehabilitation complexity of patients in order to justify health care cost and resource utilisation (228). The INTERMED is an instrument which was developed to measure case complexity in medically ill patients. It is based on the bio-psychosocial model of illness and considers many aspects including social situation, psychological aspects, co-morbidities and health systems (229, 230). However, the use of the instrument is limited due to the time required to complete (20 minutes); training requirements; questionable psychometric properties and the emphasis on risk assessment of psychiatric disease rather than physical rehabilitation (229, 231, 232). Examples of more recognised models are that of Case Mix Groups (CMGs) used in America and based on functional dependence as defined by the FIM score (233, 234). Australia utilise two different function-related case mix systems for rehabilitation, one based on the Barthel Index score (BI) (235, 236) and the other on the FIM (237). Patients are referred to a variety of specialist services based on their outcome scores and need for specialist intervention and staffing levels (238).

After considering a variety of different case mix and costing models, the Rehabilitation Complexity Scale version 2 (RCSV2) (239) was chosen as part of a battery of assessment for use in neuro-rehabilitation in the UK (220, 238). The RCSV2 provides a simple classification of rehabilitation inputs provided by nursing, medical and therapy staff while considering specialist equipment and care needs (Table 1.1; Appendix 1). The higher the score, the more complex are the patients' rehabilitation needs. In the UK this scale, combined with several other measures are integrated into a model to describe case mix complexity and a five tier multilevel tariffs for neuro-rehabilitation (220, 240). Although this scale is recommended for use in the UK trauma system (241), its utility has not been evaluated in this patient population (242).

Table 1.1 Rehabilitation Complexity Scale Version 2

Rehabilitation Complexity Score (RCSV2)					
Care or Risk	**Nursing**	**Medical**	**Therapy-Disciplines**	**Therapy-Intensity**	**Total Score (0-15)**
0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3	0 1 2 3	**……/15**

The application of the RCS in trauma will permit the measurement of rehabilitation needs of trauma patients. These data could be compared with ISS score data to investigate the relationship between rehabilitation needs and injury severity. This information, together with data on rehabilitation access and timing could be used to review funding structures and aid in the development of evidence based rehabilitation standards. In turn, data can be used to improve health care service delivery by developing rehabilitation case mix and cost models to evaluate effectiveness of trauma rehabilitation programmes. This has not been undertaken in trauma care or trauma systems in the UK.

1.6 The International Classification of Function, Disability and Health (ICF) as a proposed framework for trauma

Development and appraisal of the ICF

The development of the ICF as a modern biopsychosocial model to classify health has been described earlier in this chapter. The ICF is comprehensive in that it includes various dimensions that can impact on disability such as physical, individual and societal perspective while considering the impact of contextual factors such as the environment and personal context. The ICF is part of the World Health Organisation family of international classifications of which the ICD-10 is the most well-known. The ICD-10 is mainly used as an etiological framework to classify disease, disorders and other causes of death where the ICF is used to classify and categorise health. Information from both classifications can be used as summary measures of population health (99). The conceptual framework of the ICF enables consistent assessment of health outcome and health system performance using a standardised classification system and language (243). More than 191 member states of the WHO have agreed to adopt the ICF to standardise the scientific collection of health and disability data worldwide (244).

The ICF consists of three parts and six components which together provides and overview of the function, disability and health of an individual (Figure 1.2). Part one describes the health condition referring to the disease, disorder or trauma. Part two describes functioning in terms of body structures (s), body functions (b) and activities and participation (d). Here function refers to how the body functions both physiologically and mentally and different anatomical structures of the body. Functioning of the individual is captured as part of activity components and ability to carry out everyday tasks. Functioning in society is represented by participation and participating in the society and important life situations (184). Part three contains contextual factors which are both environmental (e) and personal. Environmental factors form the context of the persons' life such as their physical environment, their attitude to services and engagement in society. Personal factors are not part of a health condition but refer to gender, age, personality and life experience which provides background to an individuals' life. Functioning refers to all intact body functions, body structures and activities, participation and the interaction between these components. Disability on the other hand is used to describe impairments in body structures, body functions, activity limitations, and participation restrictions. The relationship between impairment, activity, and participation is not linear, and can be further impacted by contextual factors, including personal and environmental factors. This is an important difference from the initial ICIDH where the relationship between pathology, impairment, disability and handicap was assumed linear and there was no consideration of contextual factors (245, 246).

Despite the overall positive response to the publication of the ICF there are some shortcomings. Several critics highlight that activities and participation are categorized together in comparison with the ICIDH where disability and handicap were two very distinctly different concepts. It was initially perceived that if concepts are conceptually distinct, they should be categorized separately (247, 248) . However, it was recognized that users could differentiate between activity and participation domains in a number of different ways which are summarized in Annex 3 of the ICF classification (245). One study proposed that activity limitation relates to the capacity to perform an activity in an optimum environment, whereas participation restriction refers to performance in the individuals usual environment (249). However, factor analysis within this study showed no difference between activity and participation concepts when quantifying the capacity versus the extent of difficulty an individual has with a task, suggesting that there is little difference between the capacity-performance paradigms. Others have suggested

separating activities that characterise an individual such as activities of daily living (ADL) including bathing, dressing, eating, walking, and talking, various combinations of which may be required to fulfil social roles. This was compared to categories which typically relate to participation activities, including social roles (such as earning a living, parenting, and leisure activities), fulfilling religious and civic roles (spouse, parent, and citizen), all of which can be fulfilled in a variety of ways (248). In addition, some attempts have been made to map existing measures onto the ICF to determine to what extent participation is captured in frequently measured tools (250). However, the measurement of participation continues to be debated as this is a difficult construct to quantify in a hierarchical scale with ranked items (251). Others have developed measures of participation (252). Several studies emphasize the importance of operationalizing the concepts of participation when selecting measurement tools to ensure consistency throughout its measurement and appropriateness for the task at hand (251, 253).

Another criticism of the ICF is that of neglecting the importance of Quality of life (QOL). This concept is not included in the ICF per se and several authors have suggested that QOL should be included to evaluate overall life satisfaction (247, 248). However, separate constructs of subjective wellbeing or QOL could add to further confusion and if included these need to be separate constructs (248). Yet, there is no published evidence to suggest that the ICF intended to evaluate the subjective perception of how a person feels about their ability to perform a task.

The current structure of the ICF captures the degree to which functions are problematic for an individual and does not take into account if these problems actually matter to the person (184). The inclusion of personal perceptions, meaningfulness, intentions and aspirations into the personal factors component could possibly capture personal perceptions of an individual and has been suggested (254). Moreover, personal factors are not coded in the ICF due to the wide cultural variability. However, personal factors are critical to understanding performance and may explains why one patient recovers better than another based on their personal predisposition to deal with changes in health and subjective experience of disability. Closely related to personal factors are values and beliefs (181). If rehabilitation is concerned with changing behaviour in an adaptive manner, then working with patients to determine their goals demands more than an understanding of the activity limitations and participation restrictions, but also needs an understanding of values and beliefs that lead to the prioritization of one goal over another. Moreover, the ICF

manual recommends classifying what people actually do on a specific occasion, rather than taking into account of whether people actually intend or want to act in a certain way. These aspects are of utmost importance when considering person centred rehabilitation as one individual is fundamentally very different from another.

A final criticism of the ICF is the need to integrate pathology and the model of illness (181). Capturing changes in disease over time, such as deteriorating or progressive conditions will enable optimal strategies and treatment for disability management over time. An effort to link the ICD and the ICF is underway to capture the impact of health conditions in the context of the ICD-11 (255).

Structure of the ICF

ICF codes and categories are structured similar to ICD-10 codes and comprises of approximately 1400 categories that are arranged in a hierarchically organized structure with increasing levels indicating increasing degree of detail. Each component (body structure, body function, activity and participation and environmental factors) is represented by a letter and consists of several chapters and each chapter has several categories. Each category is represented by an alphanumerical code starting with a lower case letter indicating the component (b, s, d or e), followed by a number. The letters are followed by a numeric code for the chapter number (one digit, first level), followed by the second level category (two digits), and the third and fourth level categories (three and four digits). Third and fourth levels are sub-categories of the overall second level category; for example, b1 Mental functions' (first/chapter level), b114 *Orientation functions'* (second level), b1142 *Orientation to person* (third level), b11420 *Orientation to self* (fourth level) (Table 1.2). Personal factors do not currently have any categories or codes. The interaction between the five components is used to gain a holistic perspective of the function and health of individuals.

Table 1.2 Hierarchical structure of the ICF categories – Activity and participation example

Level	**Example**	**Coding**
Chapter	Chapter 4: Mobility	d 4
Second level	Walking	d 450
Third level	Walking short distances	d 4501

Using the ICF in practice

The ICD utilises different methods and investigations to make a diagnosis. Similarly, the ICF classification helps to structure, order and convey information on function, disability and health (184). The classification and a common language of the ICF can be used to systematically describe disability and human functioning and the impact of health conditions on function in a structured way (256). The bio-psychosocial framework of the ICF integrates the biological aspects of an individual and the societal perspective of health and disability to enable a coherent view of health from different perspectives. As patient centred care becomes more important, the ICF can be used to classify and collect patients and service providers' perspective on outcome. It is important to consider that the ICF is not a measurement tool but rather a classification and model providing guidance on what to measure, organising assessment components to improve clinical judgement. It acts as a reference to organise information in a common system which could lead to the development of a classification based tool to organise large quantities of information and to ensure quality (184). Different sources of information can be combined into a rating scale to indicate the extent of impairments, functional limitations and environmental barriers and facilitators.

For this reason an ICF qualifier scale was developed to be used with the ICF categories and applied in the components of *Body Function, Body Structures* and *Activity and Participation.* The categories range from 0-4 (Table 1.3). Environmental factors also has scores for barriers (-1 to -4) and facilitators (1 to 4) which can either be negative (barriers), positive (facilitators) or neutral (0). However, this scale has received much criticism in the literature due to the large intervals which were not developed with modern scale development such as Rasch modelling and showed poor responsiveness to change (257-260). More recent ICF studies are exploring the use of the Rasch model to develop more sensitive and responsive interval scales (259, 261, 262).

Table 1.3 ICF qualifier scale

0	No problem	0-4%
1	Mild problem	5-24%
2	Moderate problem	25-50%
3	Severe problem	50-95%
4	Complete problem	96-100%

Although the classification is exhaustive, it is very complex to apply all 1400 categories on a daily basis in routine clinical practice. It was thus essential to develop practice-friendly tools to enable the application of the ICF. Initially an ICF-checklist was developed containing the most relevant ICF categories (125 categories) for clinical purposes. The checklist can be used to identify and measure a persons' functioning with an abridged version of the ICF (263). Although the checklist was initially used, researchers went on to develop other tools and Core Sets to facilitate implementation of the ICF into clinical practice.

In an effort to make the ICF more accessible, several generic instruments based on the ICF were developed to enable application across a variety of conditions. Examples of these are the World Health Organisation Disability Assessment Schedule Version 2 (WHODAS ll) (264, 265), the Impact on Participation and Autonomy Questionnaire (IPAQ) (257), the Health and Functioning ICF-60 (HF-ICF- 60) (266), the Participation Scale (267) and the Participation Measure for Post-Acute Care (PM-PAC) (268). Despite these efforts, few of these measures are used in clinical practice and the generic nature may not be applicable for specific conditions or certain situations. In an effort to compromise between the need to capture detail and the generalizability of data, the ICF requires further adaptation to meet the needs and perspectives of different users (269). For this reason much work is being undertaken internationally to develop and validate ICF Core Sets (ICF-CS) for a variety of conditions and settings. A rehabilitation core set for trauma patients does not currently exist but have been suggested by several international groups (270-273).

ICF Core Set (ICF-CS) development

ICF Core Sets were developed to facilitate international implementation and clinical application of the ICF. An ICF-CS is a selection of categories from the full ICF which are considered important and relevant to describe functioning of an individual in a specific

health care setting or with a specific health condition (274). To date 34 ICF core sets have been developed which covers a variety of conditions and situations (275). Although not developed in any particular order, these ICF-CSs' can now be clustered into three groups that relate to acute, early-post acute and a long term contexts (269, 276, 277). There are several others that relate to specific conditions or interventions such as neurological conditions (278), cardio-pulmonary conditions (279), multiple sclerosis (280), spinal cord injury (281) and vocational rehabilitation (282).

A multi-staged empirical process, using direct and indirect methods are used to identify ICF categories relevant for the rehabilitation of typical patients or a condition. The selection process is comprehensive and includes only theoretically relevant ICF categories, excluding concepts that are not essential or relevant for outcome assessment.

The development process comprises of three phases which integrates evidence from the preparatory phases (Figure 1.3).

1. The *Preparatory Phase* consists of four separate studies. One study collects evidence from the perspective of a wide variety of health care professionals (HPCs) such as doctors, nurses, therapists and psychologists. This enables the application of the ICF-CS in multi-disciplinary settings. The second study collects evidence from the patient perspective using qualitative methods. A cross sectional study use the ICF checklist for patient assessment to gather data from a clinical perspective and systematic review gathers evidence from the literature to capture the researcher perspective. All four of these individual studies produce a list of ICF 'candidate' categories relevant to the health condition or context, although the ICF categories of the separate studies may be different.

2. In *Phase 1* these 'candidate' categories are presented to expert HCPs at an international consensus conference. It is recommended that the expert HCPs are representative of the 6 WHO regions (the South East Asian, Western Pacific, the European regions, African, Eastern Mediterranean, and the region of the Americas) to enable international implementation (277). During this phase the experts agree on which ICF categories should be included in the ICF-CS. Each core set has a Comprehensive and a Brief version. The Comprehensive ICF-CS is an exhaustive list

of categories relevant to the context or health condition to enable a comprehensive description and evaluation of health and function. The Brief ICF-CS is a subset of categories from the Comprehensive ICF-CS which serves as a minimum standard consisting of the most essential categories to describe function (283).

3. *Phase 2* is the implementation and validation of the ICF-CS (284, 285).

There are detailed methodological guidance for each of these studies and phases (274, 275). Methodology related to the ICF and the aims of this thesis will be discussed later in this thesis.

Figure 1.3 Development of an ICF Core Set

<table>
<tr><th>PREPARATORY PHASE</th><th>PHASE I</th><th>PHASE II</th></tr>
<tr><td>Empirical multi-centre cross sectional study – clinical evidence</td><td rowspan="4">Consensus conference where candidate categories are reviewed and discussed
 
Development of a Comprehensive and Brief ICF Core Set</td><td rowspan="4">Implementation and validation of the ICF Core Set</td></tr>
<tr><td>Systematic literature review</td></tr>
<tr><td>Qualitative study (patient/user perspective)</td></tr>
<tr><td>Expert survey – on-line</td></tr>
</table>

Application of the ICF

From an international perspective, the World Report on Disability (82) recommends the use of the ICF as a framework and classification tool for all aspects of rehabilitation. "Rehabilitation aims to support individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in their own environments" (82). Thus, the application of the ICF has the potential to provide a standard for aspects of trauma rehabilitation. It also assists in standardising the language used for health and disability statistics which will help to harmonise approaches across sources of disability data (81, 245, 286).

The clinical application of the ICF and ICF-CS has been demonstrated in a variety of settings. On a rudimentary level, a Brief ICF-CS can serve as a minimum standard for assessment of health outcome in research and in clinical practice (243, 287). Although relatively simple, standardising assessment could improve quality of care through the identification of areas that requires improvement or development to enhance patient outcomes.

The literature describes several other methods for implementation. The first is the use of the ICF in the rehabilitation cycle (288) for assessment, goal setting, intervention and outcome evaluation (289). ICF Core Sets are particularly useful in the rehabilitation cycle as they characterise the most meaningful ICF categories for a specific conditions to enable accurate assessment and outcome evaluation. ICF-CSs have been applied as part of the rehabilitation cycle in a variety of conditions including spinal cord injury (290), lower back pain (291), stroke (104) and psychiatry (292). An abridged example of how a few ICF-CS categories could be used as part of a rehab-cycle is presented in Appendix 13.

The second method is validation studies where the truthfulness, discrimination and feasibility of the ICF-CS is evaluated in the population it was designed for (101). Several validation studies have been undertaken and include ICF-CSs for osteoarthritis (293, 294), stroke (295, 296) and the ICF-CS for early post-acute rehabilitation. The third and more recent approach to the application of the ICF is the development of clinical measures of function, using Rasch methodology otherwise known as Item Response Theory (IRT) (297, 298). Such studies have been undertaken for a variety of conditions including vestibular disorders (262, 299) although this approach is not yet widely applied in the literature or clinical practice.

In addition to improving patient care, the ICF can also be used for developing policies, and evaluating the provision of resources, services and funding on an institutional, regional, national and global level (300). Moreover, there is a significant increase in the application of the ICF in social and health care systems (103-107). For example, the rehabilitation and practice component of the new German Social Code Number IX (2001) is based on the ICF and the ICF has been included on the German Health Insurance rehabilitation application form (103). In Taiwan the ICF framework is used for disability and welfare service evaluation (107) and in Portugal it is used to develop policy and practice (105). The application of the ICF continues to expand, especially in first world countries such as Germany, Canada, America, the UK and Sweden but more work needs to be done to ensure

the application in developing countries (301)

1.7 Conclusions

In the absence of standards or a framework it is evident that rehabilitation and health outcome evaluation in trauma remains unsystematic and poorly defined. The complex consequences of trauma and the prolonged recovery trajectory is not captured by trauma systems or instruments, limiting the true understanding of the burden of injury and health and social care costs. The application of a variety of measures, used at different time points post injury limits comparison of outcome at a patient level, as well as a trauma system level, locally, nationally and internationally. Moreover, despite the recognised benefits of early rehabilitation, the need, complexity or timing of access to rehabilitation is not routinely measured in trauma systems and services. Several researchers have suggested the need for the application of the ICF in trauma and the potential development of a Core Set for traumatically injured patients. However, no previous studies have actually undertaken the task of examining to what extent the ICF can be applied in trauma or developed an ICF-CS to measure health outcome after trauma.

1.8 Overall Research Objective

To development of a framework to improve rehabilitation and health outcome in major trauma patients and trauma systems

Aim 1: To evaluate the performance of the Rehabilitation Complexity Scale (RCSV2) to identify rehabilitation need after trauma

Study 1A: A prospective pilot study evaluating the utility, feasibility and performance of the RCSV2 to measure rehabilitation needs of patients in an acute major trauma setting.

Study 1B: A prospective cohort study investigating the rehabilitation needs of patients in an acute major trauma setting in relation to their injury severity, dependency and quality of life.

Aim 2: To identify the comprehensiveness of existing outcome instruments in measuring health related outcomes after trauma

Study 2A: A systematic review of instruments used to measure health outcome following multiple injuries.

Aim 3: To identify key health outcomes for trauma patients using the ICF framework as a basis for future core set development

Study 3A: A quantitative international on-line survey to investigate the functional and health problems experienced by people with multiple traumatic from an expert health care professional perspective.

Study 3B: A qualitative study using semi-structured patient interviews to investigate the patient perspective of functional and health problems after multiple traumatic injuries.

Study 3C: To combine and compare data obtained in the previous two studies to identify candidate categories for a proposed ICF-CS for trauma.

Chapter 2: METHODS

2.1 Introduction

The notion of combining qualitative and quantitative methods is becoming more popular and acceptable in the research community and there is support that deductive and inductive approaches can be complimentary to answer a research question (302). Previous perceptions suggesting that methodologies cannot be combined within a study are being challenged in support of mixed methods (303). A mixed methods approach combines elements of qualitative and quantitative methodologies in a single study and converge results, using triangulation to determine truthfulness or validity of results (302, 304). Data collection can be concurrent or sequential with exploratory or explanatory designs (303). Data integration can take place at different stages of the study such as at the data collection stage, during analysis or at the interpretation stage (305, 306). A combination of qualitative and quantitative methods with the same sample of participants could provide detailed information which is helpful in understanding or exploring a phenomenon (306). Some studies use a transformative approach to empower social change (307). This approach can require a lot of resources in terms of time and personnel, especially in sequential designs. However, despite several benefits of this approach, multiple methods have been used rather than the application of a structured mixed methods methodology. The mixed methods approach described in this thesis was chosen because the objective of the research was not to seek internal validity of results (308) nor to do explanatory research, but rather generate confirmatory knowledge of rehabilitation needs and health outcomes important in trauma.

This thesis consists of several individual studies. This approach was chosen to investigate and describe the current knowledge of rehabilitation needs, complexity, priorities and health outcome following traumatic injury. Quantitative methods were used in aim one which consisted of two cohort studies, evaluating rehabilitation needs of trauma patients. The subsequent two aims contain studies that applied the ICF as a conceptual framework. A quantitative approach was applied in aim two for the systematic review. Aim three consists of one qualitative study and two quantitative studies. A quantitative on-line questionnaire was used in study 3A to investigate if HCPs regard the ICF Acute and Post-acute core sets categories relevant to trauma patients. In study 3B the main focus was to

explore patient perceptions of health problems after traumatic injury. Although the research question was broad, by exploring patient perception of health outcome different aspects of health were contextualised with a semi-structured interview template. Thus, although the approach was qualitative, the analysis was more deductive to generate ICF categories. Study 3C compared data obtained from the previous two studies to propose candidate categories for an ICF Core Set for Trauma. This research received ethical approval from the City Road and Hampstead Research Ethics Committee on the 3rd January 2011 (11/LO/1876).

Theoretical framework

A pragmatic positivist approach was chosen for the majority of studies contained in this thesis in an effort to generate knowledge (309) rather than to interpret knowledge. This deductive approach was chosen to ensure independence as a researcher and to allow analysis of data, determine association and generalisation of findings (310). In order to meet aim three, some of the data was collected using a qualitative approach. This approach was not taken from a pure qualitative paradigm as the overall aim of the research was not to interpret or to describe what participants have in common while they experience a phenomenon (311, 312). Interpretive phenomenology, which explores the essence, experience or meanings of everyday life experiences (307) was thus not considered. Other inductive approaches such as grounded theory which generates theory, and ethnography which explores behaviours, social interactions and perceptions within communities were considered but were not appropriate for this study. Qualitative research often utilises a specific theoretical approach which provides the researcher with different 'lenses' to look at complicated issues (313). In turn the theoretical approach provides a framework in which data is analysed (313). Therefore, for the qualitative component of this research the ICF framework was used as a conceptual framework, which enabled the analysis of health concepts experienced by trauma patients. Qualitative data was linked to quantitative categories to facilitate a greater understanding of patient problems within the holistic health framework (314). Several other qualitative approaches were considered during the design of the study but regarded as unsuitable. More detail of the approaches considered and reasons for exclusion can be found in Appendix 10.

2.2 Methods used for Study 1A

Study 1A: A prospective pilot study evaluating the utility, feasibility and performance of the RCSV2 to measure rehabilitation needs of patients in an acute major trauma setting.

2.2.1 Study design

Study 1A is a single centre prospective pilot cohort study. Cohort studies, although not experimental in design, are useful observational studies due to their temporal framework which can determine association and examine multiple outcomes over time. A pilot study was chosen to conduct preliminary analysis of the RCSV2 in trauma prior to committing to a large scale study. The pilot study was conducted over one month.

2.2.2 Data collection

Patients admitted under the trauma service at the Royal London Hospital (RLH) were identified and recruited 48 hours after admission. Forty eight hours was chosen as inclusion criteria to ensure patients could be evaluated after the weekend and that injuries sustained required hospitalisation and not just observation. Data was collected for one month. Rehabilitation Complexity Scale v2 (RCSV2) and Barthel Index (BI) (236, 315) scores were collected twice a week during multi-disciplinary team (MDT) meetings. Patients who were already in the hospital from the previous month were scored on the RCSV2 and BI on the first day of the month of the pilot. The researcher Karen Hoffman (KH) attended MDT meetings to facilitate the application of the measures and to collect the data for each patient, once the scores were agreed by the MDT. Patient demographics and injury severity scores (ISS) were collated from the RLH trauma registry. Data on length of stay and discharge destination were also collected.

Instruments used

Chapter one, provided an overview of the variety of measures used to measure complexity of care and the application of the RCS within the UK context. The RCS was originally developed to provide a simple measure of rehabilitation inputs provided by a variety of health care professionals to describe case mix complexity based on rehabilitation and clinical needs (239, 240). The initial RCS was adapted and reliability and construct validity was established for the Rehabilitation Complexity Scale version 2 (RCSV2) in neurological rehabilitation (239).

Within rehabilitation research several measures of disability are used, of which the Barthel Index (BI) and the Functional Independence Measure (FIM) are the most common (316, 317). The BI was chosen above the FIM for this study as the BI scores were already routinely collected as part the nursing care plan on the trauma ward. The BI measures performance in activities of daily living, toileting, continence, mobility and transfers and has high validity and reliability (236, 318-325). It is quick to score, required no training or specialist skills (326, 327) and nursing staff were familiar with the terms.

Rehabilitation Complexity Scale version 2 (RCSV2)

The RCSV2 (239) was used to measure rehabilitation complexity basic care and support need. An example can be found in Appendix 1, Table 1.1 and Table 2.1. The scale is divided into care needs (C: 0-3), nursing dependency (N: 0-3), medical need (M: 0-3), therapy in terms of the number of therapy disciplines (TD: 0-3) and overall therapy intensity (TI: 0-3). A patient requiring specialist nursing for tracheostomy care will score (N: 3) and (M:3) if they require medical management in intensive care. A score of 0 indicates no need and a score of 3 indicates very complex needs in each category. The total score for the RCSV2 is 15, thus the higher the score, the more complex are the rehabilitation needs of the patient. The RCSV2 was categorised into 4 standard subgroups (220) to enable categorical data analysis: 'Low' (1-6), 'Moderate' (7-9), 'Heavy' (10-12) and 'Very Heavy' (13-15) rehabilitation needs.

Barthel Index 100 point scale

The BI 100 point scale was used to evaluate disability. An example can be found in Appendix 2. The 100-point Barthel was used and grouped into categories of disability described in the literature (328, 329): 'None' (Independent - 80-100), 'Minimal' (60-79),'Partial' (40-59) and 'Very' disabled (0-39). A low score indicated severe disability and a high score minimal disability.

Injury Severity Score

The injury severity score was obtained from the RLH trauma data base. Severe injury were regarded as ISS>15. ISS scores were grouped into injury severity categories to enable categorical data analysis. These groups were ISS<9 (mild), ISS 9-15 (moderate), ISS 16-24 (severe) and ISS>24 (very severe) categories. These categories are used in trauma literature

and more recently for funding structures such as the NHS standard contract for major trauma services (217, 330).

2.2.3 Data analysis

Statistical analysis was performed using GraphPad PRISM v5 (331). Normality was assessed using normal-quantile plots and non-parametric statistics were used throughout. Proportions were analysed using chi squared for proportion of patients discharged home. Non-parametric data for the ISS, RCSV2 and BI were compared using the Mann Whitney U test. The Wilcoxon signed-rank test was used for same group comparison for change in BI scores. One way analysis of variance (Kruskal Wallis test) was used to compare categorical data and change scores between the RCSV2, BI, ISS and length of stay. Spearman's coefficient was used to determine the degree of correlation between variables for the RCSV2, BI and the ISS. The strength of correlation was categorised as 0 (zero), 0 -0.3 (weak), 0.4-0.6 (moderate), 0.7-0.9 (strong) and 1 (perfect) (332). A p value of <0.05 was considered statistically significant.

2.2.4 Potential for bias

Some patients spend long periods in the hospital which could skew the data. To reduce selection bias these patients were included into the data set. As an occupational therapist my attendance at MDT meetings could cause observer bias or even interview bias in terms of the amount of prompting given to MDT members to complete the RCSV2 and BI scores. Several MDT members were involved in scoring patients using the outcome measures to reduce observer bias (333) with minimal prompting from the primary researcher.

2.3 Methods used for study 1B

Study 1B: Prospective cohort study investigating the rehabilitation needs of patients in an acute major trauma setting in relation to their injury severity, dependency and quality of life.

2.3.1 Study design

The pilot study provided encouraging data in terms of the utility of the RCSV2. As a result a prospective longitudinal cohort study was designed. Prospective cohort studies have a benefit of collecting specific data, detailed in a study protocol, to enable more explicit and complete data collection than in pilot or retrospective studies (334). However, prospective cohort studies require a large sample of patients, recruited over a period of time and can be very labour intensive if too many variables and time points are selected.

2.3.2 Data collection

The study was carried out at the RLH, Major Trauma Centre. A convenience sample of sequential patients who met inclusion criteria (described in 2.2.2) was recruited over a year during their in-hospital stay. No formal sample size was calculated. Patients who were already in hospital at the start of the study were included and measures were applied for their ability at the time, similar to the pilot study. Admission scores and discharge scores for rehabilitation needs and disability were collected twice a week during MDT meetings for included patients. The researcher (KH) attended MDT meetings to facilitate the application of the instruments and to collect the data for each patient, once the scores were agreed by the MDT. Discharge QOL data was collected in addition to rehabilitation and disability data. Planned discharge dates were set during MDT meetings. An awareness of discharge dates enabled face to face administration of the EuroQol by the researcher (KH) with patients prior to discharge. A convenience sample of a smaller cohort of patients was asked to complete a postal questionnaire of the EuroQol at three months post discharge.

Instruments

Rehabilitation Complexity Scale Extended (RCS-E)

At the time of the pilot study (Study 1A), the RCSV2 was the accepted scale used in neurological rehabilitation. After the initial pilot study the RCS-E was published (335). The RCSV2 was revised and the RCS-E was developed in response to clinician feedback. The

RCS-E overcomes ceiling effects in therapy subscales and better identifies patients with highly complex therapy and equipment requirements which was absent from the RCSV2 (335). A validation study found a strong correlation between the RCSV2 and RCS-E where the RCS-E demonstrated added benefit in its ability to capture more complex patient needs (335). Specialist equipment is often a consideration in trauma care ranging from mobility aids to braces and external fixators. With this in mind I chose to use the RCS-E for the larger longitudinal study.

The RCS-E is a 20 point scale instead of a 15 point scale. It measures patient rehabilitation complexity and need in terms basic care and support need (C: 0-4), nursing dependency (N: 0-3) and medical need (M: 0-3). Therapy needs are divided into therapy disciplines (TD: 0-4) and therapy intensity (TI: 0-4). Equipment needs (E: 0-2) is a new category. A score of 0 indicates no need and a score of 3 or 4 indicates very complex needs in each category, e.g. specialist nursing care for trachea care (N:3) or need for medical management in intensive care (M:3). Rehabilitation complexity were divided into 4 standard subgroups: 'Low' (1-6), 'Moderate' (7-9), 'Heavy' (10-13) and 'Very Heavy' (14-20) rehabilitation needs (336). An example of the actual scale is included in the Appendix 3. Table 2.1 presents an overview of the differences between the RCSV2v2 and the RCS-E

Table 2.1 Comparison between the RCSV2 and the RCS-E

	RCSV2	**Range**	**RCS-E**	**Range**
C/R	Basic care	0-3	Basic care or risk	0-4
N	Specialist nursing needs	0-3	Specialist nursing needs	0-3
T	Therapy disciplines	0-3	Therapy disciplines	0-4
	Therapy intensity	0-3	Therapy intensity	0-4
M	Medical needs	0-3	Medical needs	0-3
E	N/A	N/A	Equipment/ facilities	0-2
	Total	**0-15**	**Total**	**0-20**

Barthel Index 20 point scale

The 20-point Barthel Index (BI) (327, 337) was used to measure disability on admission and discharge. The 20-point BI was chosen over the 100-point BI which was used in the pilot study as the MDT found it easier to use and interpret scores. The 20-point and the 100-point BI is equivalent in content and the change in scoring value does not affect the clinimetric properties of the scale (338). The BI scores were grouped into categories of disability (327): 'None' (Independent – 16-20), 'Minimal' (11-15),'Partial' (5-10) and 'Very' disabled (0-4). A score of 20 is independent and a score of 0 is fully dependent. An example of the scale is included in Appendix 2.

Table 2.2 Comparison between the BI 100 point scale and the BI 20 point scale

	BI 100 point scale	**Range**	**BI 20 point scale**	**Range**
1.	Bowels	0-10	Bowels	0-2
2.	Bladder	0-10	Bladder	0-2
3.	Grooming	0-5	Grooming	0-1
4.	Toilet use	0-10	Toilet use	0-2
5.	Feeding	0-10	Feeding	0-2
6.	Transfers	0-15	Transfers	0-3
7.	Mobility	0-15	Mobility	0-3
8.	Dressing	0-10	Dressing	0-2
9.	Stairs	0-10	Stairs	0-2
10.	Bathing	0-5	Bathing	0-1
	Total	**0-100**	**Total**	**0-20**

In addition to using clinician rated measures I wanted to capture a broader sense of health outcome from the patient perspective. I chose to use the European Quality of Life Questionnaire (EuroQol) (126) as a patient rated outcome measure (PROM) to evaluate quality of life. It does not require payment for licencing agreement such as the SF-36. Moreover, the EuroQol is very quick to administer thus reducing patient burden and was therefore ideal for use in a busy acute trauma setting.

European Quality of Life Scale (EuroQol)

The EuroQol (126) is a standardized generic measure of health status, which provides a simple descriptive profile and a single index value for health status. It was designed for self-completion, it is cognitively simple and takes only a few minutes to complete (85). The data derived from the EuroQol is converted into a single index value that can be used in economic and clinical evaluation of health care and in population health surveys (339). The EuroQol is often used in population studies to compare the impact of disease on quality of life.

The validity and reliability of the EuroQol in its ability to measure health related quality of life has been demonstrated in other conditions (340-345). There are no specific reliability and validity studies of the EuroQol in trauma although it is used generally in the trauma literature (127, 346, 347) and in global burden of disease studies (124, 348) which justifies the appropriateness for its use in this study.

The EuroQol consists of two sections. Section one has five dimensions consisting of mobility, self-care, usual activities, pain or discomfort and anxiety or depression. An example of the EuroQol can be found in Appendix 4. The respondent has three choices for each dimension- no problem (1), some problems (2) and unable to do (3), for which they tick a box next to the most relevant statement. Section two has a visual analogue scale (VAS) asking people to rate their overall health status. This ranges from '100' which is the best possible health to '0' which is the worst possible health. There are 243 possible EuroQol health states. A single summary score, known as a Time Trade-off (TTO) score, is calculated from the combined scores of the five dimensions and overall perception of general health based on the VAS value. TTO values range from -0.594 to 1, where negative values are valued as worse than death and one is the best possible health (349). Time Trade-off (TTO) scores were calculated and used for analysis (339) and the UK value set was used.

2.3.3 Data analysis

Analysis of RCS-E, BI and ISS data and statistical methods used were similar to that in the pilot study and was previously discussed in section 2.2.3. Overall EuroQol TTO scores for each RCS-E category were compared to investigate the relationship between rehabilitation need and quality of life using the Kruskal Wallis test. The five individual EuroQol dimensions were also compared to RCS-E categories using the Kruskal Wallis test to investigate the relationship between components of QOL and rehabilitation needs.

2.3.4 Summary

Aim one consists of two cohort studies which aim to investigate rehabilitation requirement of trauma patients. This data can assist in improving trauma systems through the provision of adequate rehabilitation at the most appropriate time to improve outcome and quality of life of patients.

2.4 ICF methodology used for Aim 2 and Aim 3

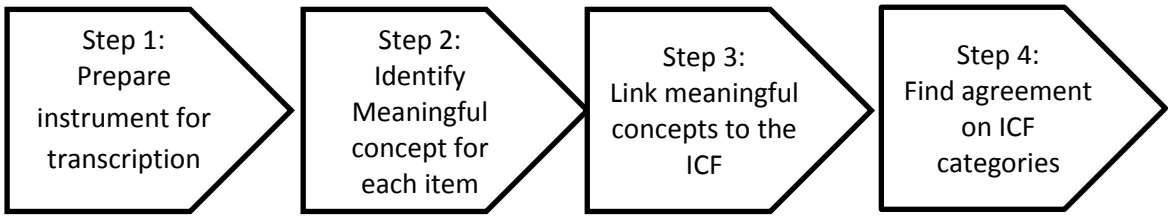
The ICF was used as the conceptual framework for all studies conducted for aim 2 and aim 3. Within the next section I will discuss ICF Core Set development methods which were used within Study 2 and Studies 3A-3C studies (aim 2 and aim 3). An overview of the phased development of an ICF-CS was given in Chapter One. During the course of my PhD I was able to address several stages related to the preparatory phase for the development of an ICF-CS for trauma, for which I conducted individual studies. Due to the heterogeneity of the trauma patient population and several other pragmatic reasons the ICF-CS methods were adapted where necessary.

The study conducted to meet aim 2 was a systematic review of outcomes measures used in studies of function and disability after major trauma. Three studies were undertaken to meet aim 3; a quantitative on-line questionnaire to gather HCP perspectives on health outcome after trauma; and a qualitative study to investigate patient perspectives of health outcome following trauma; and finally a study combining results from the previous two studies.

2.4.1 Linking concepts to the ICF

The process of linking was used in the systematic review (Aim 2) and in the patient interviews (Aim 3B) to identify ICF concepts contained in outcome measures and patient interviews. The technique of 'linking' is an important methodological process used to identify ICF categories for ICF-CS development. Established linking rules (350, 351) provides guidance on the process of identifying meaningful units and concepts contained in outcome measures or interview text which are then linked to ICF categories.

Figure2.1 Steps involved to link concepts to ICF categories



'Linking' of items contained in an outcome measures will be used to demonstrate the process of linking. Each outcome measure has a different number of items or questions. For example, the Medical Outcome Study Short Form Health Survey (SF-36) (128) has 36 items (questions) compared to the Functional Independence Measure (FIM) (155) which has 18 items (questions).

The linking process consists of essentially 4 steps (Figure 2.1 and Table 2.3):

1. Write down each individual question/item contained in the outcome measure on a separate line, or in the interviews it would be each sentence from the transcribed interviews.

2. In a second step, identify all meaningful concepts for that specific question/item or sentence. One item can contain one or more meaningful concepts. For example, 'Do you get tired when walking'? 'Get tired' is a meaningful concept related to endurance or fatigue and 'walking' relates to mobility (Table2.3).

3. Once all meaningful concepts are identified, they are linked to the most relevant ICF category. Endurance could be linked to exercise tolerance (b455) which is a category in the *Body Function component*. 'Walking' is linked to walking (d450) which is a category contained in the mobility chapter in the *Activity and Participation component* (walking: d450).

4. In a final step ICF categories are discussed and agreed if more than one researcher is used to carry out the linking of items.

Table 2.3 Example of linking of items contained in outcome measures

Step 1:	**Step 2:**		**Step 3:**		**Step 4:**
List each item separately. Each question is one item.	Each researcher identifies the meaningful concept independently.		Each researcher decides independently which ICF category corresponds to the meaningful concept.		The researchers discuss any discrepancies and agree on one category.
Item	**Concept** Researcher 1	**Concept** Researcher 2	**Category** Researcher 1	**Category** Researcher 2	**ICF category agreed on**
'How would you rate the pain in your knee?'	Pain in knee	Knee pain	b28016 Pain in joints	b28016 Pain in joints related to s75011 Knee	b28016 Pain in joints

In this thesis, a second researcher (EC) linked and compared 40% of data in the systematic review and 5% of data for patient interviews to reduce research bias and ensure data accuracy.

2.4.2 Frequency analysis

Frequency analysis was used in the systematic review (Aim 2, Chapter 5) and in the patient interviews (Aim 3B, Chapter 7). The purpose of frequency analysis is to establish which ICF categories occur frequently where ICF linking is used. Frequencies are divided into relative and absolute frequencies and reported as percentages.

Relative frequency refers to the number of times an ICF category occurred per outcome measure or per interview, once all duplicates are removed. Each category is counted only once. The relative frequency is used to establish how many ICF categories are contained per outcome measure or per interview.

Absolute frequency is the total number of times an ICF category occurred, thus counting each time an ICF category was linked to a concept in either an outcome measure or patient interview. The absolute frequency indicates how frequently a specific ICF category occurs in a specific outcome measure or how frequently a specific category is experienced by patients. This helps to grasp the impact or occurrence of specific health issues. For example; 10 patients from a possible 20 patients may mention pain. The relative frequency of pain will be 50%. However, these 10 patients may mention pain 30 times during the interview which gives an absolute frequency of 150%.

Relative and absolute frequencies were calculated for the total number of ICF categories in patient interviews and outcome measures rather than individual frequencies per outcome measure or per interview.

2.4.3 Summary

ICF linking and frequency analysis are specific methods used as part of ICF-CS development. Linking is an essential method to identify ICF concepts contained in data from different studies. Frequency analysis facilitates a greater understanding of the prevalence of health issues and the importance and impact these have on health outcome.

2.5 Methods used for Aim 2

Aim 2: To identify the comprehensiveness of existing outcome instruments in measuring health related outcomes after trauma

Study 2: A systematic review of instruments used to measure health outcome following multiple injuries.

2.5.1 Study design

Study 2 is a systematic review of outcomes measures used in trauma studies to evaluate which ICF categories are represented in the instruments and which health outcomes are frequently captured by these instruments.

2.5.2 Data collection

Data sources and search strategy

Many trauma outcome studies prior to 2001 used outcome measures which were developed within previous models of disability rather than the ICF (352). I specifically wanted to investigate if there were any more recent measures used in trauma studies, based on the ICF as a framework, to investigate to what extent modern-day health concepts are captured in trauma studies.

I therefore included published studies between and including 2006 and 2012 in my search in an attempt to capture outcome measures based on the new ICF classification. A 16-step electronic search strategy of English language studies was developed for Medline and adapted for EMBASE and Cumulative Index of Nursing and Allied Health Literature (CINAHL) databases. A combination of MeSH terms with four themes was used: major trauma (wound and injuries), outcome (outcome measures, tools, measures) quality of life and rehabilitation (Appendix 8).

Study selection and inclusion/exclusion criteria

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis process (PRISMA) (353) was used to identify suitable studies. Studies reported in English, published in peer reviewed journals evaluating health or rehabilitation outcome following major trauma were included. Randomised control trials, cross sectional and cohort studies of adult patients (≥18 years) with injuries involving at least two body areas or body systems were included in

order to exclude single system injuries. Excluded studies were those based on isolated spinal cord injuries or traumatic brain injuries as these have a different scope and outcomes; case studies with less than ten patients and studies which did not measure health outcome after major trauma.

Screening and data extraction

All study titles and abstracts, including reference lists were screened by two independent researchers Karen Hoffman (KH) and Elaine Cole (EC). This was done to reduce researcher bias. Once duplicates were removed, inclusion criteria were applied and studies for full text review were identified. Full text articles were reviewed by the primary researcher (KH) and a random sample of 50% were screened by a second researcher (EC). The GRADE methodology (Grading quality of evidence and strength of recommendations) was used to judge the quality of the evidence of included studies (354-357) (Appendix 5). The overall methodological quality of combined studies is not discussed in detail in this thesis as it is not relevant to the primary aim of this study although it was important to evaluate the quality of the research at the time of the study. Any discrepancies were resolved by both researchers re-reviewing the study. The information extracted from studies included: Country of publication, study design, sample size and outcome measures used. In a second step outcome measures that occurred in at least three or more studies or those which are valid, trauma specific outcome measures were identified for ICF content analysis.

2.5.3 Data analysis

Content analysis and linking to ICF

In addition to the systematic review of studies evaluating function and disability after multiple injuries, I also wanted to investigate how much of the ICF is represented within frequently used measures in trauma outcome studies. Thus, in a second step I extracted outcome measures that occurred in at least three or more studies that I included in the review or those which were valid, trauma specific outcome measures. Once the measures were identified their individual items or questions were linked to the ICF using the ICF linking methods described previously in Section 2.4.1. The primary researcher linked all identified measures to the ICF. A random selection of forty percent of concepts were also linked and compared by a second researcher (EC) to reduce researcher bias and ensure data accuracy. Linked data were compared to ICF linking results of similar measures if these occurred in other ICF publications (172, 358, 359). This was used to check validity

and accuracy of linking results where appropriate. Where items were linked to the third- and fourth-level categories they were aggregated to second level categories.

ICF frequency analysis

In a second step I examined the most frequently represented ICF categories contained in measures. This is determined by calculating absolute and relative frequencies. Frequency analysis was discussed previously in more detail in section 2.4.2. This data is useful to distinguish which health concepts and ICF categories are captured by measures frequently used in trauma studies.

ICF representation

In addition to frequency analysis, I analysed to what degree measures covered concepts contained in the ICF. These analyses are typical to ICF methodology (358) although not essential for ICF-CS development. Content density, bandwidth and content diversity of measures were calculated to establish the breadth, depth and diversity of outcome measures in relation to the ICF (358).

- Content density evaluates the ratio of the number of ICF categories contained per instrument in relation to the number of items in the instrument. Measures with smaller content density have fewer and less complex items, which makes these easier to use in clinical settings (360). A content density of one indicates that each item in the measures represents one ICF category. Greater than one indicates that each item measures more than one ICF category. For example; 'Can you walk?' contains one ICF concept whereas 'Do you get tired when you walk?' contains two concepts related to mobility and exercise tolerance. The latter example will have a greater content density as it contains more than one ICF concept. A large content density indicates that fewer questions capture more ICF concepts.

- Content diversity measures the depth or detail of the instrument. A lower content diversity indicates that several items and their concepts are dedicated to measure the same topic or ICF category (360). Thus a measure could have eight items where five items relate to mobility and three items relate to self-care. This measure will have a low content diversity as it only measures two ICF concepts. Measures with a greater content diversity measures more ICF categories.

- Bandwidth, reported as a percentage (%) measures the breadth of the instrument. It calculates the percentage of ICF categories in each instrument in relation to the total number of ICF categories (1454 categories). As I focused on second level categories, I calculated bandwidth using 363, which was the total number of second level categories rather than all 1454 ICF categories. A larger bandwidth (%) indicates that a greater number of ICF categories are included in the instrument, thus greater ICF coverage.

2.5.4 Summary

The systematic review was extended and to enable further analysis of ICF representation in measures frequently used in trauma studies. Application of the ICF methods facilitates a greater understanding of the content of outcome measures which could identify areas of health that may require additional outcome measurement.

2.6 Methods used for Study 3A

Study 3A: A quantitative international on-line survey to investigate the health problems experienced by people with multiple traumatic from an expert health care professional perspective.

2.6.1 Study Design

Study 3A is an international on-line survey, with expert health care professionals involved in the treatment and management of patients with traumatic injuries.

2.6.2 Data collection

Instrument used

The ICF-CS methods utilise a three round Delphi process to gather expert opinions on functional and environmental aspects relevant to a person with a specific health condition (274). During the development of the Acute and Post-Acute ICF Core Sets the Delphi technique was used with experts working with patients with neurological conditions, musculoskeletal and cardiopulmonary conditions (269, 361, 362). Many trauma patients might experience neurological, musculoskeletal of cardiopulmonary problems. The Acute and Post-Acute ICF Core Sets have been subject to a rigorous development process and validation studies have been completed in the aforementioned patient populations (363-365). Therefore, instead of conducting a Delphi survey specifically related to trauma I elected to use the categories contained in these ICF-CS to design an on-line questionnaire for Health Care Professionals (HPCSs). The 140 ICF categories contained in the Acute and Post-Acute ICF Core Sets (362) were presented to trauma experts to establish the relevance and importance of these health categories for trauma patients. The 140 categories presented in the on-line questionnaire consisted of 57 *body function categories*, 13 *body structure* categories, 40 *activities and participation* categories and 30 *environmental factors*. The questionnaire was delivered via an online web platform, Survey Monkey® (366).

For each category presented, experts were asked to rate the prevalence of certain problems (not common, common, very common) and the importance of the category (not important, important, very important). This rating was used to establish the prevalence and impact of health problems relevant to trauma patients. Some problems may not be

very common but can have a significant impact on outcome and should be given greater importance due to the potential impact they can have on recovery. Experts had the opportunity to add any additional items if they were of the opinion that categories were missing. These were linked to ICF categories using the linking process described previously. An example of the questionnaire can be found in Appendix 6

Sample size and recruitment

Previous ICF studies used samples of HCPs ranging from 21 to 126 (367-369). I intended to recruit a total of 150 HCPs from a variety of professional backgrounds and representative of five of the six world health regions (367) to ensure international participation and acceptability. Participation from a variety of HCPs will enhance the relevance and application of results in a multi-disciplinary setting. To account for potential poor response rates and incomplete data I aimed to recruit 220 experts with an expected response rate of 60%. A sample size calculation and a statistical power calculation were not considered appropriate for this study.

Two groups of HCPs were invited to participate. Group one was purposively selected known experts in trauma care. An expert was defined as any HCP registered with a professional body with at least five years' experience of working in trauma and able to read and write English. Trauma experts were identified via professional trauma networks, conference programmes and prominent authors of trauma literature. An e-mail invitation was sent to experts including information about the study, inviting them to participate. Those that agreed to participate received an on-line link to the survey. Completed questionnaires were monitored via a Survey Monkey® function linked to an e-mail address. This enabled analysis of response and attrition rates. In an attempt to improve response rates, two reminders were sent to HCPs that agreed to participate.

The second group of HCPs were recruited through web based invitations posted on profession specific bodies or special interest group websites. For example: members from the World Federation for Occupational Therapy and the International Society for Physical and Rehabilitation Medicine responded to an on-line invitation for participation. The reason for this was to increase awareness of the project which will promote the application and adoption of the ICF in trauma at a later stage. This process also reached HCPs that could be experts in the field despite having no research publications or conference

presentations. Consent to participate was obtained at the start of the on-line questionnaire.

2.6.3 Data analysis

Descriptive statistics was used to analyse the frequency of categories identified by health care professionals. Open ended and free text answers were analysed using the linking process described previously to identify any additional ICF categories (370, 371).

Each ICF category contained two responses. One specified how common a category was (not common, common or very common) and the other the importance (not important, important, very important). The average was calculated for responses that indicated a category was 'common or very common' and 'important or very important'. The average is presented as a percentage, representing how many HCPs regarded a specific ICF category as common (prevalent) or important. Several different 'cut off points' were considered to determine what percentage of categories indicate HCP level of agreement and are representative of frequent, relevant and important categories for trauma patients. During the ICF-CS consensus conference 75% is used to indicate agreement between HCPs. The categories presented in the on-line questionnaire were already previously discussed and presented to HCPs during the development of the Acute and Post-Acute ICF Core Sets. I thus considered the 140 categories presented potentially very relevant for trauma patients. For this reason I decided to use a conservative estimate of 50% to indicate level of agreement between HCP and ICF categories including and above 50% were included in the final analysis and manuscript.

2.6.4 Summary

This study aimed to gain a greater understanding of ICF categories, relevant to trauma patients, as identified and prioritised by trauma experts.

2.7 Methods used for Study 3B

Study 3B: A qualitative study using semi-structured patient interviews to investigate the patient perspective of health problems after multiple traumatic injuries.

2.7.1 Study design

Study 3B is a qualitative study using semi-structured interviews with individuals who experienced traumatic injuries. The purpose of patient interviews was to gain an understanding of health issues experienced by patients after sustaining a traumatic injury. The ICF was used as a framework for analysis.

2.7.1 Theoretic approach

The ICF framework was used as a conceptual framework in this qualitative study. Qualitative research often use a specific theoretical approach which provides the researcher with different 'lenses' to look at complicated issues (313). In turn the theoretical approach provides a framework in which data is analysed (313). The application of the ICF framework will enable analysis of health concepts experienced by trauma patients. Qualitative data will be linked to quantitative categories to facilitate a greater understanding of patient problems within a holistic health framework (314). Several different methodological approaches were considered during the design of the study. The approaches considered and the reasons why they were not selected are summarised in Appendix 10.

2.7.2 Data collection

The ICF core set development process suggests using either focus groups or interviews. Trauma patients are a very heterogeneous patient population. Many trauma patients have on-going complex needs or live long distances form the hospital. They also sustained their injuries in different ways, some of which may be due to self-harm or interpersonal violence. Due to the complexity of these considerations and patient confidentiality I chose to use semi-structured interview rather than focus groups. Several other data collections methods were considered but decided against for the reasons discussed in Appendix 11.

Justification for the use of semi structured interviews

Use: Semi-structured interviews are carried out face to face using an interview guide with topics listed but few specific questions. The aim is to facilitate people to talk about a certain topic using the interview guide to cover the area of interest. The guide may include initial closed questions which are followed by prompts or open ended questions to clarify information (307, 372). The ICF was used to structure the questions and prompts and an example of the topic guide can be found in Appendix 7.

Advantages: Follow up questions can provide clarification or obtain more detail (116). It enables further discovery or elaboration of information that is important to participants which may not have previously been thought of as pertinent by the research team (373). The interview is often structured with a sequence of questions to control the intensity of the interview (374). Interviewer bias is reduced through the use of specific questions which are consistent for all participants with appropriate prompts. Reflection can reduce interviewer bias and reduce the subjectivity of the interviewer (375, 376) and should be done throughout the process and in between interviews. The researcher needs to reflect on how her role as a therapist could impact on the interpretation of data or the way in which questions or prompts are phrased. The interview is structured in a non-threatening way using an introduction, warm up, main body of the interview, cool off and closure (307).

Disadvantages: Interviews are time consuming, are potentially costly and it may be difficult to analyse in-depth data to identify important themes due to the volume of data generated. The researcher needs to be mindful of the impact questions can have on individuals and a reflective approach could help to minimise harmful effects through using appropriate empathy and support (377). Some authors criticise the fact that the interview has some structure as that may imply some sort of control over the interview and what is discussed (378). Participants may expect to benefit from the interview in some way and it is important to distinguish roles as an interviewer and that of a therapeutic relationship (374). The researcher (KH) is an occupational therapist but this was not known to the participants as this could have increased their expectations of obtaining assistance with services or access to additional health care.

Conclusion: Semi structured interviews provide a framework to obtain focused information, opinions and experiences from participants, without the restriction of a fully structured

approach. The structure and the sequence of questions are helpful in providing a safe environment to discuss issues that may be difficult to discuss.

2.7.3 Population

Participants were recruited from one major trauma centre in London that admits on average 1800 patients with multiple traumatic injuries each year. Discharged adult patients and a small cohort of in-patients were approached to participate in the study.

2.7.4 Inclusion and exclusion criteria

Patients aged eighteen years or older who had sustained a traumatic injury and were able to give informed consent were included. Individuals who did not have capacity to participate or consent, e.g. severe brain injury were excluded.

2.7.5 Sampling

The process of sampling in qualitative research could be described as theoretical or purposeful rather than representative of a population, which is the goal in quantitative studies (308). Convenience samples are often used in qualitative research due to limitations in either access to participants, time or for pragmatic reasons (302).

I chose to use maximum variation sampling (376) for this study. I used this sampling to identify patients based on two criteria: injury severity (<16 and ≥16) and age (≤34 and ≥35 years old). These categories had been used in previous trauma studies (15, 379, 380). Within these categories I recruited patients with a variety of timeframes since their injury for reasons explained below. This form of purposive sampling (381) was used to obtain a wide-range of people from a very heterogeneous patient population (304, 382). Patients may experience a variety of health problems at different time periods after injury. The timeframes used to identify suitable patients were based on those used in previous trauma studies. Some longitudinal trauma studies have evaluated patients at 4, 6, 12 and 24 months post injury (71, 383-385). Whereas, a consensus document suggested evaluating quality of life at 3, 12 and 24 months post injury (160). However, another important consideration for recruiting patients was the time frame for diagnosis of Post- Traumatic Stress Disorder (PTSD). The literature highlighted the importance of evaluating patients 3 to 4 months post injury as this is the most prevalent time to experience PTSD-type symptoms (59, 386, 387). Therefore, patients within the age and ISS categories were

recruited from 1 month to 24 months post injury to encapsulate all recommended timeframes.

Sample size

Several previous qualitative studies and review articles suggested that 20 to 30 participants are sufficient to reach data saturation (302, 311, 388, 389). With this in mind I aimed to recruit 30 patients. Taking into consideration study withdrawal, patients' lost to follow up and non-interested patients I decided to approach 45 patients with the aim of recruiting 30 patients. It is clearly documented in the trauma literature that up to 50% of patients can go lost to follow up due to the transient population (390-392).

2.8.4 Recruitment

Patients are routinely contacted via a telephone call at different time frames following discharge as part of the Trauma Outcomes Unit (TOU) follow up procedure. On average 300 patients are contacted each month who are anywhere between 1 to 18 months post injury. After application of the sampling and inclusion criteria, patients were informed about the study during the routine follow up call and invited to participate. A patient information leaflet and a consent form were sent to patients that expressed an interest to participate, which was followed up by a phone call a week later. During this follow up phone call a suitable time and date for interview was agreed with those patients who wanted to participate. Written consent was obtained when patient attended the interview.

Interviews were scheduled to coincide with other hospital appointments where possible to reduce patient burden. A private room was made available with a speaker phone if any patients preferred to complete interviews over the phone. A small sample of in-patients was invited to participate during routine TOU discharge visits. Patient information leaflets were given to patients who expressed an interest. They were approached after 24 hours to establish their decision. At this time the interested patients provided written consent and a suitable time was arranged for the interview in a private location in the hospital. In and out patients were assured that refusal to participate would in no way jeopardize their health care.

2.7.5 Instruments and data collection

An interview guide containing 6 questions based on the components *Body Structures, Body Functions, Activities and Participation, Environmental Factors* and *Personal Factors* of the

ICF was used to structure questions. Additional open-ended questions were used to prompt patients if they had difficulty understanding the question. An example of the topic guide can be found in Appendix 7.

The researcher conducted all the interviews. All interviews were digitally recorded and brief anonymised notes were taken during the interview where necessary, to aid with the reflective process. Recordings were transcribed verbatim by the researcher.

2.7.6 Data analysis

Transcribed interviews were analysed using the meaning condensation procedure (393, 394). This method was chosen as it is the data analysis method used to develop ICF-CSs (395, 396) and is effectively the same process as the ICF linking process. There are some similarities to thematic analysis where at a first level, labels are attached to groups of words (307), however themes are not developed. In a first step the transcribed interviews were read through to get an overview of the data collected. In a second step the data was grouped into meaningful units. In a third step the meaningful units are linked to ICF categories. The linking process was discussed previously in section 2.4.1 and Table 2.4 has an example of this. Where items were linked to the third- and fourth-level categories, they were aggregated to second level categories.

Table 2.4 Qualitative data analysis and linking

Interview text	Meaning unit	ICF category
"One of my problems is that I struggle to **concentrate on things**..."	Restrictions in concentrating on things	b140 Attention functions
"I can't **hike or cycle anymore** "	Unable to hike Unable to cycle	d920 Recreation and leisure (*d9201 Sports*) d475 Driving (*d4750 Driving human-powerded transportation*)

Frequency analysis

Absolute and relative frequencies were calculated for ICF categories identified in patient interviews. Frequency analysis is discussed in detail in Section 2.4.2. Relative frequency refers to the number of patients who mentioned a specific a category, thus the category was recorded only once per interview despite possibly being mentioned several times. Absolute frequency was the total number of times a category was mentioned, where some patients may mention the same category or concept more than once. For example, several patients may mention *pain* several times during the interview. Thus the absolute frequency of *pain* may be greater than 100% if it was mentioned very frequently and more times than the number of patients included in the study. The absolute frequency was used to capture the *magnitude* of the concepts where the relative frequency was used to establish the *prevalence* of concepts or categories.

Once ICF categories were identified, a descriptive summary of the data was sent to patients who were asked if the summary captured all important aspects discussed during the interview. This process of member checking, sometimes referred to a respondent validation (304), was completed in an effort to increase data accuracy and validation (397). Categories reported by more than 5% of patients were considered for inclusion in the final analysis and manuscript.

2.7.7 Summary

The ICF framework was used for qualitative data collection and data analysis. This consistent application of the ICF framework in several different studies will enable a greater understanding of health problems faced by trauma patients, using a consistent language.

2.8 Methods used for Study 3C

Study 3C: To combine and compare data obtained in the previous two studies to identify candidate categories for a proposed ICF-CS for trauma.

This study is different to the previous studies in that it combined data collected in Study 3A and Study 3B and proposes candidate categories for an ICF-CS for Trauma. Data collection was thus completed in the previous two studies.

2.8.1 Data analysis

Categories that were identified as prevalent or important by more than 50% of HCPs and categories identified by 5% of patients were combined and compared to explore agreement and differences between ICF categories. Further criteria were applied to the data to identify the most relevant and important categories from both a patient and HCP perspective. For HCP data, all categories with a prevalence and importance of > 70% were included. 70% was chosen to ensure adequate level of agreement between AHPs and to include the most relevant categories (398). For patient data, all categories which had a patient identified relative frequency of >15% were included to present high frequency categories (399). The reduced data of these two studies are presented and discussed in Study 3C.

2.9 Summary

This chapter discussed and justified methodological approaches, study designs and data collection methods chosen for each individual study. The following chapters will describe each study in more detail including the results and implications for practice.

Chapter 3: PILOT STUDY OF REHABILITATION NEEDS OF TRAUMA PATIENTS

3.1 Introduction

As trauma survivors increase, so does the prevalence of long term disability (400, 401) and the need for rehabilitation (170, 402). Acute rehabilitation, as discussed in Chapter one, has shown potential to prevent the development of secondary complications (207, 403), adverse effects of immobility and reduce overall length of stay in other conditions (25, 210). However, the evidence describing rehabilitation complexity, effective rehabilitation interventions, rehabilitation intensity or timing is lacking in the trauma literature (197).

Rehabilitation needs assessment and rehabilitation intervention in a trauma population is challenging due to the heterogeneity of injuries that patients may have (50). The measurement of rehabilitation complexity currently relies on surrogate measures of injury severity (404), disability (405), nursing staffing levels (406) or care dependency (407). These often poorly reflect actual therapy need and therefore have limited utility for individual patients or health services (25, 240). No previous studies have investigated rehabilitation complexity in acute trauma and its relationship to injury severity and disability (408). The lack of an appropriate tool to measure rehabilitation needs and benchmark therapy provision is a key barrier in trauma systems design and optimisation.

The overall objective of this study was to evaluate the potential utility of the Rehabilitation Complexity Scale version 2 (RCSV2) (239, 240) in measuring acute rehabilitation needs of trauma patients. Secondly I wanted to investigate how the RCSV2 performs in relation to injury severity and disability measures.

3.2 Methods

3.2.1 Study design and setting

This study was a single centre pilot cohort study evaluating the utility and feasibility of the RCSV2 in an acute major trauma centre. The trauma service has a dedicated 15 bedded trauma ward, although patients may be admitted to other wards or critical care due to clinical or organisational necessity. The pilot took place over one calendar month.

3.2.2 Inclusion criteria

Adult trauma patients (≥18 years) admitted to the trauma service and who had a minimum length of stay of 48 hours or more were included for one month.

3.2.3 Instruments

The RCSV2 and the BI was used to measure rehabilitation needs and disability. These are discussed in more detail in Chapter two. The RCSV2 was categorised into 4 standard subgroups: 'Low' (1-6), 'Moderate' (7-9), 'Heavy' (10-12) and 'Very Heavy' (13-15) (220). The 100-point Barthel was used and grouped into categories (328) of disability described in the literature: 'None' (Independent - 80-100), 'Minimal' (60-79),'Partial' (40-59) and 'Very' disabled (0-39). ISS scores were obtained from the trauma data base at the RLH and categorised into minimal (ISS<9), moderate (ISS 9-15), severe (ISS 16-14) and very severe (ISS>24) categories. This was done to enable categorical data analysis.

3.2.4 Recruitment and data collection

Rehabilitation need and disability scores were administered twice a week during multi-disciplinary team meetings. The researcher (KH) attended MDT meetings to facilitate the application of the instruments and to collect the data for each patient, once the scores were agreed by the MDT. Admission scores were collected for all eligible patients. Patients that were already in the hospital from the previous month were scored on the RCSV2 and the BI on the first day of the month. Demographic details and injury characteristics were obtained from the contemporaneous trauma registry at the RLH including age, gender, ISS, mechanism of injury and length of stay.

3.2.5 Data analysis

Statistical analysis was performed using GraphPad PRISM v5 (331). Normality was assessed using normal-quantile plots and non-parametric statistics were used throughout. Proportions were analysed using chi squared for proportion of patients discharged home. Non-parametric data for the ISS, RCSV2 and BI were compared using the Mann Whitney U test. The Wilcoxon signed-rank test was used for same group comparison for change in BI scores. One way analysis of variance (Kruskal Wallis test) was used to compare categorical data and change scores between the RCSV2, BI, ISS and length of stay. Spearman's coefficient was used to determine the degree of correlation between variables for the RCSV2, BI and the ISS. The strength of correlation was categorised as 0 (zero), 0 -0.3 (weak), 0.4-0.6 (moderate), 0.7-0.9 (strong) and 1 (perfect) (332). A p value of <0.05 was considered statistically significant.

3.3 Results

Over the 30-day period 178 acutely injured adult patients were admitted to the trauma service. 103 patients met the inclusion criteria with a length of stay of 48 hours or more. 41 patients were already in hospital at the start of the study and the remainder were admitted during the course of the study. Patient demographics and injury characteristics are shown in Table 3.1. It took two minutes per patient to complete the full RCSV2 assessment. In general multi-disciplinary therapy teams and nurses agreed on the care, nursing, medical and therapy needs of patients, although inter-rater reliability was not formally evaluated. Initially clinicians required prompting to consider all rehabilitation interventions such as cognitive and psychosocial limitations and not just physical impairments. This improved during the course of the month as clinicians became more familiar with the RCSV2. No other issues were identified during the acute hospital admission period that inhibited the administration of the RCSV2.

Table 3.1 Study population characteristics

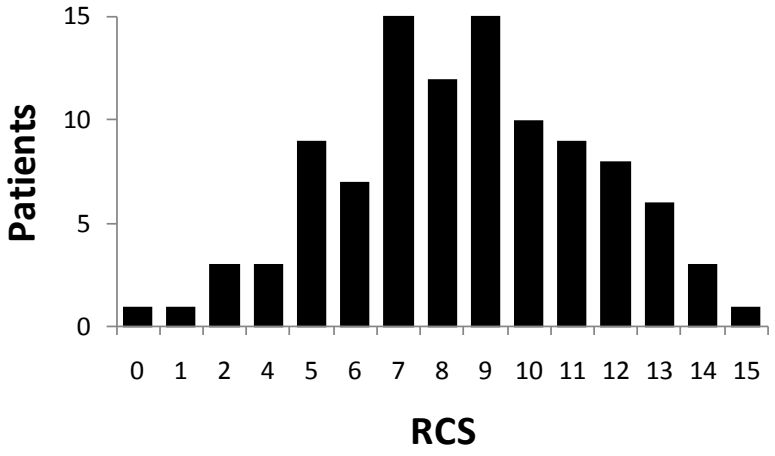
	All patients	RCS 1-6 (Low)	RCS 7-9 (Moderate)	RCS 10-12 (Heavy)	RCS 13-15 (Very Heavy)
N	103(100%)	23(22%)	42(41%)	27(26%)	11(11%)
Male (%)	82(80%)	19(83%)	32(76%)	22(81)%	9(82%)
Age	32(25-47)	30 (22-41)	30 (24-47)	41(27-52)	36 (23-53)
ISS	14 (9-25)	5 (2-10)	9 (8-18)	24 (17-34)	29 (25-40)
ISS >15 (%)	50(47%)	5(13%)	13(31%)	21(78%)†	11(100%)‡
RCSV2	9(7-11)	5 (4-6)	8 (7-9)	11 (10-12)	13 (13-14)
BI	30(0-55)	70 (60-85)	45 (26-50)	0(0)	0(0)
LOS (days)	13(6-28)	3 (2-12)	12 (7-22)	24 (12-52)	33 (32-70)
Discharged Home (%)	71(69%)	19(83%)	32(76%)	15(56%)	5(45%)*

Values are given as number (%) or median (inter quartile range). ISS: Injury Severity Score, LOS: Length of Stay. One way analysis of variance (Kruskal Wallis test) was used to test change across categorised data.

† ISS>15 Low RCSV2 vs Heavy RCSV2 (χ^2) p<0.0001
‡ ISS>15 Low RCSV2 vs Very Heavy RCSV2 (χ^2) p<0.0001
* Discharged home (χ^2 for trend) p<0.0001

The median RCSV2 score was 9 (IQR: 4). The distribution of RCSV2 scores were normal with 46% of patients categorized as either 'Heavy' or 'Very Heavy' (Figure 3.1A, Table 3.1).

Figure 3.1A The RCSV2 shows a normal distribution of scores across the patient population.



There was a strong correlation between the RCSV2 and injury severity (r =0.69, p <0.001). Severely injured patients (ISS >15) had significantly higher RCSV2 scores than patients with mild/moderate trauma (RCSV2: 10 vs 7, p <0.001 – Figure 3.1B). However there were some notable discrepancies between injury severity and rehabilitation need. 11% of patients with mild/moderate injury (ISS ≤15) has RCSV2 scores in the 'Heavy' or 'Very Heavy' range, while 33% of severely injured patients had only 'low' or 'medium' rehabilitation complexity. Conversely 25% of patients with a 'low' or 'moderate' RCSV2 were severely injured (Table 3.1). While the RCSV2 is consistent with injury severity the rehabilitation needs of individual patients cannot be estimated purely from their injury severity score.

Figure 3.1B Box and whisker plot showing median, IQR and adjusted range for rehabilitation complexity in relation to injury severity

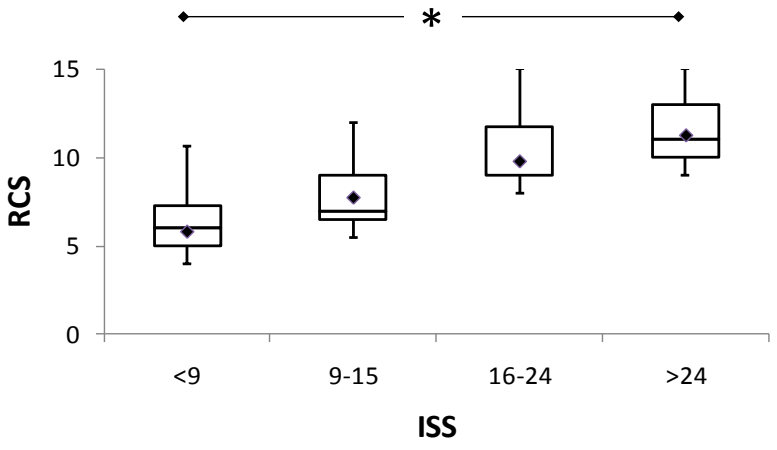


Figure 3.1B Box and whisker plot showing median, IQR and adjusted range for rehabilitation complexity in relation to injury severity (lower of: maximum value or 3Q+1.5*IQR).
◊=mean. Kruskal-Wallis Test significant at p<0.001 across all ISS groups.

The distribution of admission BI scores was very different from the RCSV2 distribution (Figure 3.2A). 39 (36%) of patients were classified as being totally disabled (BI: 0), while a further 39 patients were partially or very disabled (BI: 1-59). There was a strong statistical correlation between the BI and injury severity (r =0.71, p <0.001) but there was a wide range of disability scores for each ISS group (Figure 3.2B). The BI's relationship to injury severity appeared to have a flooring effect in that 94% of severely injured patients were

classified as 'Very disabled' of which 71% were totally disabled (BI of 0). The BI has a broad discriminatory range for moderately injured patients but less so for more severely injured patients (Figure 3.2 B) where the RCSV2 shows more discrimination for patients with severe injuries.

Figure 3.2A The Barthel Index shows and abnormal distribution

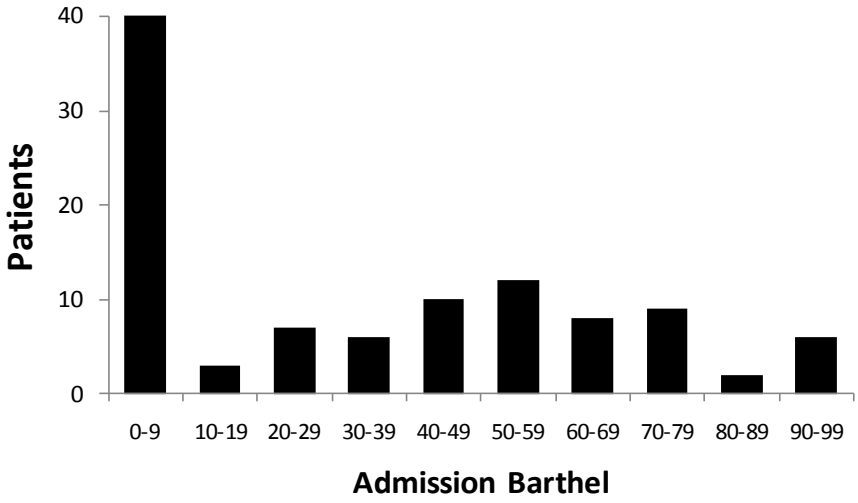


Figure 3.2A 39% of patients are completely dependent with a BI value of 0/100.

Figure 3.2B Box and whisker plot showing median, IQR and adjusted range for disability in relation to injury severity

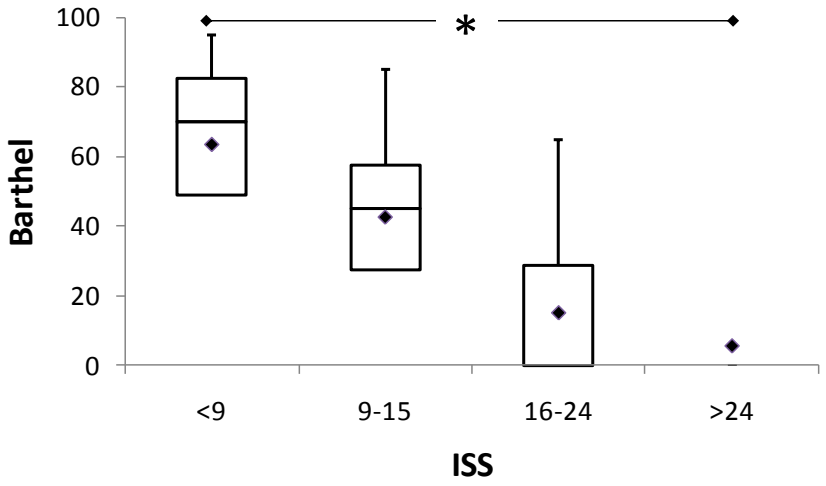


Figure 3.2 B Box and whisker plot showing median, IQR and adjusted range. ◊=mean. Kruskal-Wallis Test significant at p<0.001 across all ISS groups. BI showed a flooring effect, categorising 94% of patients with an ISS>15 as very disabled.

The RCSV2 was statistically closely correlated to the BI (r =0.91, p <0.001 – Figure 3.2C). However there were clinically important discrepancies between the measures. The group

with ‘low’ or ’moderate’ RCSV2 scores had a median BI of 50 which would predict high rehabilitation needs due to disability. The RCSV2 also had a broader range than BI for patients with higher injury severities who tended to fall within the ‘very disabled’ category. Of the 58 patients classified as ‘very disabled’ by the BI, 21 (36%) had low or moderate rehabilitation complexity (Figure 3.2D).

Figure 3.2C Box and whisker plot showing median, IQR and adjusted range for rehabilitation complexity in relation to disability

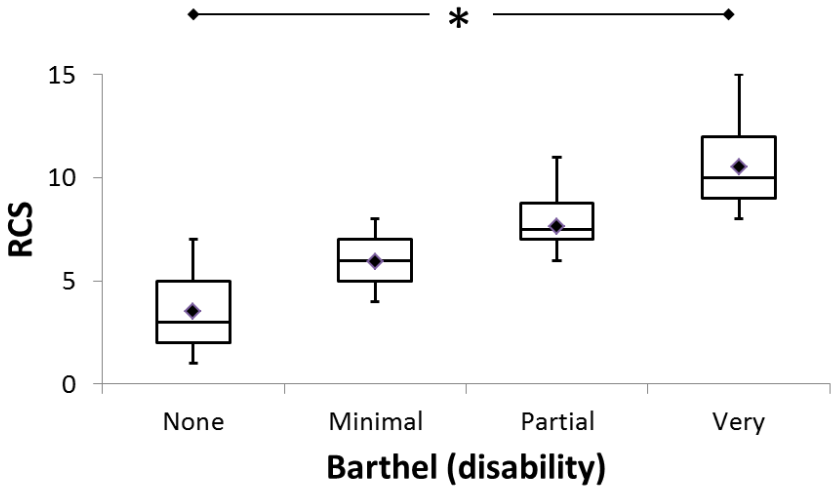


Figure 3.2C Box and whisker plot showing median, IQR and adjusted range. ◊=mean. There is a strong correlation between RCSV2 and BI, r=0.91, p<0.001.

Figure 3.2D Distribution of RCSV2 scores within BI disability categories

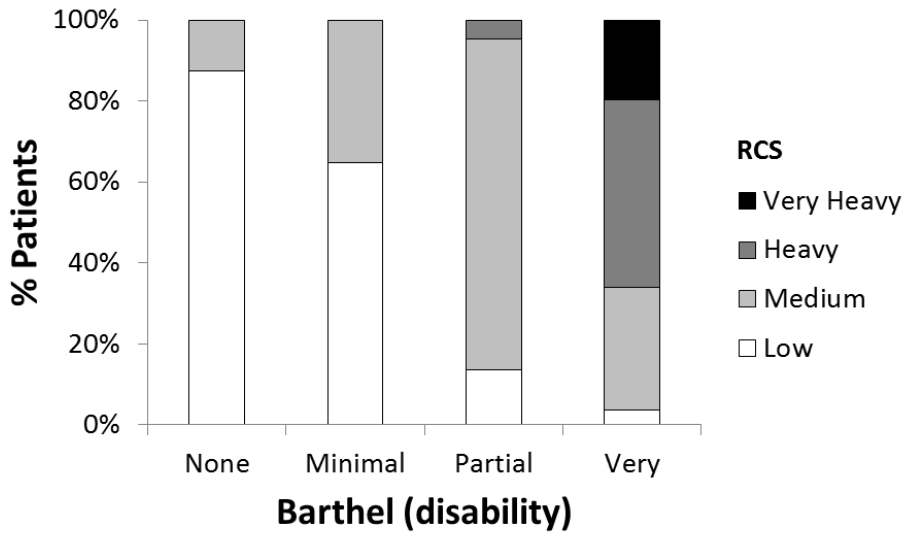


Figure 3.2D Distribution of RCSV2 scores within BI disability categories. The RCSV2 identified a broader range of rehabilitation complexity than the BI for patients with more severe injuries.

Of the 58 patients classified as partly or very disabled, 21 (36%) had low to moderate rehabilitation complexity. Patients' rehabilitation complexity was correlated with their length of stay (r =0.64, p<0.001 – Figure 3.3A). Overall the RCSV2 was better at predicting hospital stay than the ISS (r =0.48, p<0.001). The BI had a similar statistical correlation to hospital stay (r =0.68, p<0.001) but again showed poor discrimination in the patients with high disability scores (Figure 3.3B).

Figure 3.3A Box and whisker plot showing median, IQR and adjusted range for length of stay in relation to rehabilitation complexity

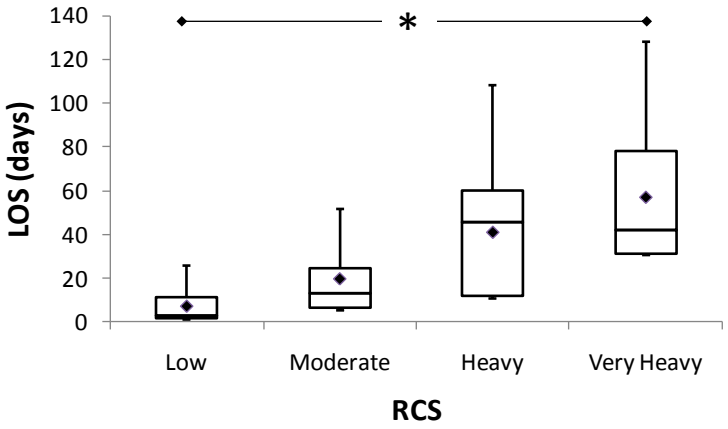


Figure 3.3A Box and whisker plot showing median, IQR and adjusted range. ◊=mean. Kruskal-Wallis test was significant at p<0.001 across all RCSV2 categories in relation to length of stay.

Figure 3.3B Box and whisker plot showing median, IQR and adjusted range for length of stay in relation to disability

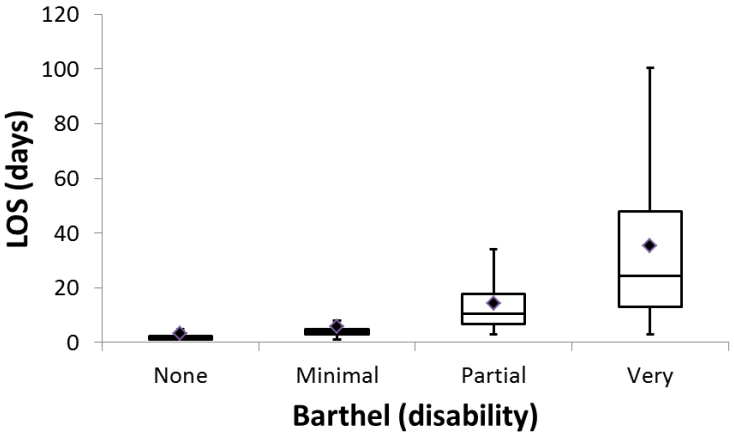


Figure 3.3B Box and whisker plot showing median, IQR and adjusted range. ◊=mean. Kruskal-Wallis Test was significant at p<0.001 across all BI categories in relation to length of stay. The spread of disability data has poor discrimination and a flooring effect is seen despite close statistical correlation.

The RCSV2 was able to identify patients whose disability scores were likely to improve during their hospital admission (p=0.036 - Figure 3.3C). Patients with a low rehabilitation complexity were more likely to be discharged home, and the RCSV2 showed good discrimination in discharge prediction (Figure 3.4D). In contrast the BI was not associated with discharge status. Patients classified by the BI as independent, minimal and partially disabled were equally likely to be discharged home (75%, 88% and 91% respectively). 54% of patients in the 'very disabled' category were discharged home and even 46% of patients initially classified as totally disabled (BI: 0) went home.

Figure 3.3C Bar chart showing the change in disability in relation to rehabilitation complexity which was significant across all RCSV2 categories

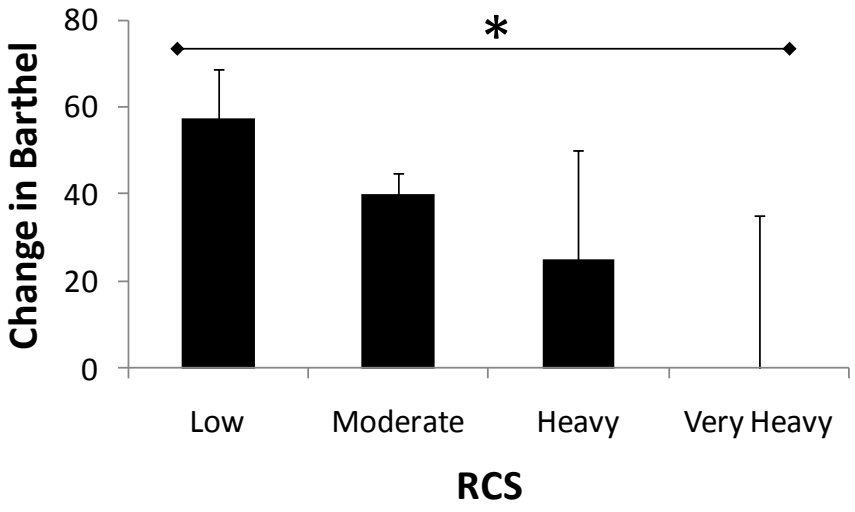


Figure 3.3C The Kruskal Wallis test is significant across all RCSV2 categories p=0.036. Low RCSV2 categories had the biggest change in disability scores. Very little change is seen in the very heavy RCSV2 category.

Figure 3.3D Proportion of patients discharged home decreased as rehabilitation complexity increased

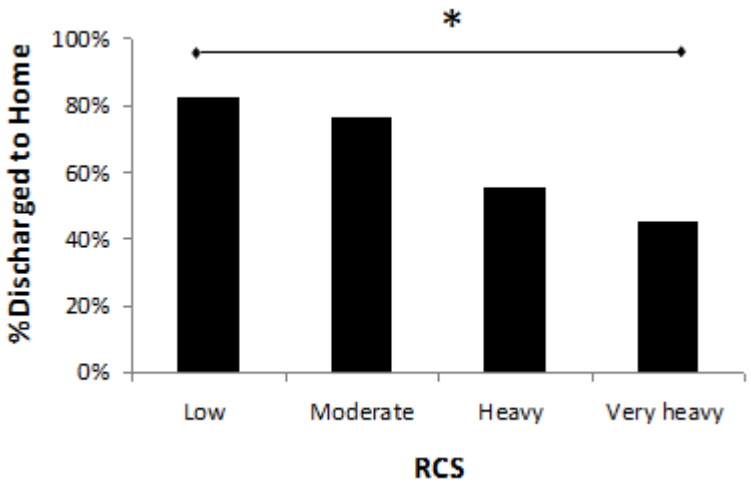


Figure 3.3D Proportion of patients discharged home decreased as rehabilitation complexity increased. Chi square for trend demonstrates a statistical significant difference between groups $p<0.0001$.

3.4 Discussion

This is the first prospective cohort study examining the utility of the RCSV2 in acute trauma patients. It was possible to use the RCSV2 in a busy clinical environment, thus demonstrating the feasibility of use. The RCSV2 outperformed the ISS and the BI in its ability to identify rehabilitation requirements in relation to injury severity, rehabilitation complexity, length of stay and discharge destination. This confirms findings of previous studies demonstrating a non-linear relationship between admission and discharge BI scores and that admission BI scores are unable to predict discharge status (409).

The RCSV2 appears appropriate to assess rehabilitation complexity of severely injured patients. The literature suggests that early acute rehabilitation can reduce disability (410, 411). Despite this, the specifics for early rehabilitation interventions in trauma have not been defined (408). However, the categorisation of RCSV2 data shows promising data on complexity categories of trauma patients. Although the data does not suggest which rehabilitation interventions will be beneficial in an acute setting, it is a first step in defining rehabilitation complexity of trauma patients using measures other than the ISS or disability. This is an important finding not previously investigated in the trauma literature. Moreover, the structure of the RCSV2 is suggestive of a rehabilitation prescription including dose (how many therapists and staff are required) and frequency (how often/how many hours).

Analysis of the relationship between rehabilitation dose and frequency could provide data on the benefits of rehabilitation and effectiveness and accuracy of the RCSV2 as a rehabilitation prescription.

Despite the strong correlation between the RCSV2 and the BI they do appear to measure different constructs. The data distribution in itself are very different with the RCSV2 displaying a normal distribution compared to the BI which is skewed toward very disabled scores. The RCSV2 showed good discrimination in for this patient group when compared to the BI which lacked discrimination and exhibited 'flooring effects' (410). Disability and dependency measures are frequently used in clinical practice and research to evaluate patient need and outcome but they do not necessarily capture the complexity of patients in terms of care or rehabilitation requirements (228). The RCSV2 captures a level of complexity in terms of resource requirements and intensity not previously investigated in trauma.

The added level of complexity measurement the RCSV2 offers may have a role in the evaluation and development of systems and funding structures for acute trauma rehabilitation. While disability measures (BI) and functional measures (FIM) have been used to develop funding models (405, 412) they do not measure actual rehabilitation requirements and do not capture complex nursing, medical or therapy requirements. Moreover, the RCSV2 has been shown to identify gaps in service delivery by quantifying the discrepancy between rehabilitation prescription and provision (25, 239). This may provide information for the development of effective and resource-efficient trauma rehabilitation services. It is thus essential to consider rehabilitation needs assessments as well as diagnostic and disability measures when developing rehabilitation services, funding structures or systems.

The correlation between rehabilitation needs and length of stay and discharge destination is of great importance and an unexpected result. There is currently no tool used in acute trauma to assist in clinical decision making to predict discharge time frames or discharge destination. Pilot data demonstrates that the RCSV2 has potential to support timely decision making with regard to discharge destination and length of stay. These are important hospital based performance criteria which could contribute in reducing length of stay and improve resource utilisation. This has not been investigated or demonstrated in previous trauma studies.

3.4.1 Limitations and weakness

There are several limitations to this pilot study. First, the feasibility (413) of administration of the RCSV2 through formal assessment of inter-rater reliability or the duration of assessments was not completed. However, it was possible to successfully incorporate the RCSV2 into a multidisciplinary acute trauma service, indicating its potential for acceptance in this environment.

Second, rehabilitation need was only measured on admission limiting longitudinal analysis of change in rehabilitation requirements and thus resource requirements. This was due to the continuous movement of patients from the trauma ward for the orthopaedic and neuro-surgery services. Effective systems and resources to track patients throughout the hospital would enable date completeness and data quality and should be considered for longitudinal studies. This was not possible at the time due to resource limitations in terms of the researchers' time and other commitments.

Thirdly, data was collected over one month with a small sample size. I did not follow all patients from admission to discharge, due to the short time frame. Some patients were already in the hospital at the start of the study and their initial RCSV2 scores may not have reflected their true admission RCSV2.

3.4.2 Conclusion

The RCSV2 is potentially a feasible and useful tool for the assessment of rehabilitation complexity in acute trauma care. In this pilot study the RCSV2 showed consistency with injury severity and disability but provided additional information on patients' rehabilitation requirements. It was recognized that a larger sample is required to enable generalization of findings. With this in mind I explored the possibility of a larger, longitudinal study to investigate the potential of using the RCSV2 to measure change in rehabilitation needs in relation to disability and quality of life.

Chapter 4: REHABILITATION NEED AND QUALITY OF LIFE FOLLOWING MAJOR TRAUMA

4.1 Introduction

In the previous chapter the pilot study demonstrated that it is feasible to use the RCSV2 in a busy acute setting during MDT meetings and ward rounds. It was possible to group patients into complexity categories using a measure other than the ISS. Moreover, the RCSV2 showed promising potential in predicting hospital based outcomes such as length of stay and discharge destination. However, the small sample (n=103) limited detailed evaluation of sub categories of patients of different injury severities, limiting generalisation of results. A larger data set with more variables would allow more detailed analysis of rehabilitation needs in relation to patient complexity and important hospital outcomes.

Longitudinal admission and discharge data would enable evaluation of the change in rehabilitation needs in relation to disability and injury severity. This could generate new insight into the recovery and rehabilitation needs of trauma patients which could assist in exploring possible components of a rehabilitation prescription. Moreover, it will enable further clinimetric evaluation (338, 414) in terms of responsiveness of the RCSV2 in acute trauma care.

In addition, I wanted to explore the relationship between rehabilitation complexity and quality of life. Some studies suggested that QOL can be used as an outcome and QOL measurement should be included into routine clinical practice (415). The significant increase in the use of PROMs in variety of health conditions is evidence of this (416-418). There are currently no established trauma PROMs and QOL is not routinely measured in acute care (17).

The objective of this second study was to evaluate the change in patients' rehabilitation complexity in relation to their disability, injury severity and quality of life. I also wanted to investigate if it is feasible to evaluate QOL in an acute trauma setting.

4.2 Methods

More detailed information on methods related to this study can be found in Chapter 2.

4.2.1 Study design

This was a prospective, longitudinal cohort study at one major trauma centre in London. Admitted trauma patients were recruited over a 12 month period.

4.2.2 Inclusion and exclusion criteria

Adult patients (≥18 years old) admitted to the trauma service with a minimum stay of 48 hours were included.

4.2.3 Instruments

Disability and rehabilitation measures are discussed in Chapter 2. The Rehabilitation Complexity Scale- extended version (RCS-E) (335) was used instead of the RCSV2 version 2 (239) which was used in the pilot study (419). The RCSV2 was revised to develop the RCS-E in response to clinician feedback. The measure overcomes ceiling effects in therapy subscales and captures carer risk and equipment requirements absent in the RCSV2 (335). Rehabilitation complexity were divided into 4 standard subgroups: 'Low' (1-6), 'Moderate' (7-9), 'Heavy' (10-13) and 'Very Heavy' (14-20) rehabilitation needs (336).

The 20-point Barthel Index (BI) (327, 337) was used to measure disability on admission and discharge. The 20-point BI was chosen over the 100-point BI which was used in the pilot study as the MDT found it easier to use and interpret scores. The 20-point and the 100-point Barthel Index is equivalent in content and the change in scoring value does not affect the clinimetric properties of the scale (338). The BI scores were grouped into categories of disability (327): 'None' (Independent – 16-20), 'Minimal' (11-15),'Partial' (5-10) and 'Very' dependent (0-4).

QOL was evaluated using the European Quality of Life Scale (EuroQol) (126). The EuroQol is often used in population studies to compare the impact of disease on quality of life. Time Trade-off (TTO) scores were calculated and used for analysis (339). TTO scores are calculated from combined scores of five dimensions and overall perception of general health on a visual analogue scale (VAS). The dimensions are mobility, self-care, usual

activities, pain or discomfort and anxiety or depression. Each dimension has three response options. Level 1 =No problem (Independent), Level 2 =Some problems (Moderate) dependence, Level 3 =Unable to do (Dependent). TTO values range from minus 0.594 to 1, where negative values indicate a QOL as worse than death and one is the best possible health. Overall general health, measured with the visual analogue scale (VAS) ranges between 0-100 where 100 is the best possible health and 0 the worse possible health.

4.2.4 Data collection and recruitment

Data was collected twice a week during ward rounds and multi-disciplinary team meetings over one year. Patients that were already in hospital at the start of the study were included, similar to the pilot study. Disability and rehabilitation scores were collected on admission and before discharge to measure change in rehabilitation complexity and disability. Quality of life scores (EuroQol) were collected face-to-face prior to discharge. A sub sample of patients was asked to complete a postal questionnaire of the EuroQol at three months post discharge. Demographic information and injury characteristics were obtained from the contemporaneous trauma registry including age, gender, injury severity and length of stay.

4.2.5 Data analysis

More detail on statistical analysis is available in Chapter 2. The same significance (*p*-values) and strength of correlation values were used as for the pilot study. Non-parametric statistics were used throughout. Spearman's coefficient was used to determine the degree of correlation between variables for the RCS-E, BI, ISS and the EuroQol. Chi squared test was used to analyse the proportion of patients discharged home and transferred to rehabilitation. The Mann Whitney U test was used to compare the RCS-E, BI and ISS scores prior to categorisation. The Wilcoxon signed-rank test was used for same group comparison for change in RCS-E and BI scores. One way analysis of variance (Kruskal Wallis test) was used to compare categorical data and change scores between the RCSV2, BI, ISS, EuroQol and length of stay.

Overall EuroQol TTO scores for each RCS-E category were compared to investigate the association between rehabilitation complexity and quality of life using the Kruskal Wallis test. The five individual EuroQol dimensions were also compared to RCS-E categories using

the Kruskal Wallis test to investigate possible associations between components of QOL and rehabilitation complexity.

4.3 Results

Over the year recruitment period approximately 1600 adult patients were admitted to the trauma centre with nearly half (n=809) being eligible. Admission data was collected for 458 patients (57%) and complete data sets (admission and discharge data) were available for 307 (67%) of patients. Patient demographics and injury characteristics are shown in Table 4.1. The median age was 38 years and patients had an above average injury severity (ISS=17) with nearly half of the patients (n=138) having major trauma (ISS>15). The median length of stay (22 days) was also above average (9 days), possibly due to five patients that had a length of stay greater than 100 days with the maximum length being 435 days. On admission patients had high rehabilitation needs (RCS-E=10) and were partially disabled (BI=7).

Table 4.1 Demographic data for 307 patients admitted and discharged

	All Patients	RCS 1-6 (Low)	RCS 7-9 (Moderate)	RCSV 10-13 (Heavy)	RCS 14-20 (Very Heavy)
N	307 (100%)	46 (15%)	89 (29%)	123 (20%)	49 (2%)
Male (%)	240 (78%)	39 (85%)	70 (79%)	95 (77%)	37 (76%)
Age (range)	38 (16-95)	25 (16-73)	30 (16-95)	39 (16-87)	35 (17-83)
ISS (range)	17 (1-59)	9 (1-31)	9 (1-51)	16 (1-59)	25 (1-59)
ISS >15 n (%)	138 (45%)	9 (20%)	22 (25%)	67 (54%)	40 (82%)
Admission RCS-E (range)	10 (8-13)	6 (4-6)	8 (8-9)	12 (11-13)	14 (14-15)
Discharge RCS-E (range)†	6 (4-9)	3 (2-4)	5 (3-6)	8 (6-10)	11 (8-12)
Admission BI (range)	7 (2-12)	15 (13-16)	11 (8-13)	5 (1-7)	0 (0)
Discharge BI (range) †	15 (12-18)	19 (17-20)	16 (14-19)	12 (11-15)	11 (4-13)
Length of stay (range)	22 (2-435)	4 (3-30)	7 (2-75)	17 (2-115)	28 (4-435)
Discharge home (%)	239 (78%)	45 (98%)	81 (93%)	91 (75%)	19 (41%)

† Wilcoxon signed-rank test is significant for same group comparison across all RCS-E and BI categories ($p<0.0001$).

The Kruskal-Wallis test was significant ($p< 0.0001$) across all RCS-E categories in relation to disability categories measured with the BI (Figure. 4.1A). At discharge patients improved overall by one RCS-E category compared to two categories on the BI (Figure 4.1B). Patients

in the 'Very Heavy' rehabilitation group improved by two BI categories from very dependent to minimal dependence, despite on-going rehabilitation requirements (Table 4.1, Figure 4.1B). Clinically the BI showed poor discrimination in patients with 'Very Heavy' rehabilitation requirements (Fig. 4.1A) despite a strong statistical correlation with the RCS-E on admission (r=-0.819, p<0.0001) and discharge (r=-0.742, p<0.0001).

Figure 4.1A Admission rehabilitation complexity in relation to disability

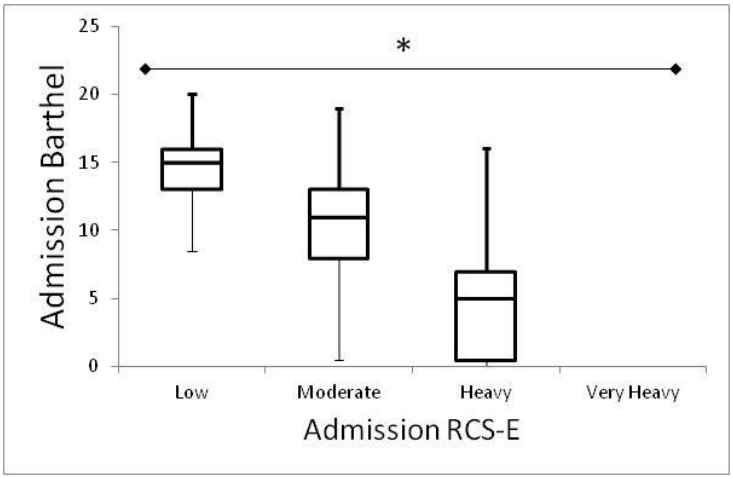


Figure 4.1B Discharge rehabilitation complexity in relation to disability

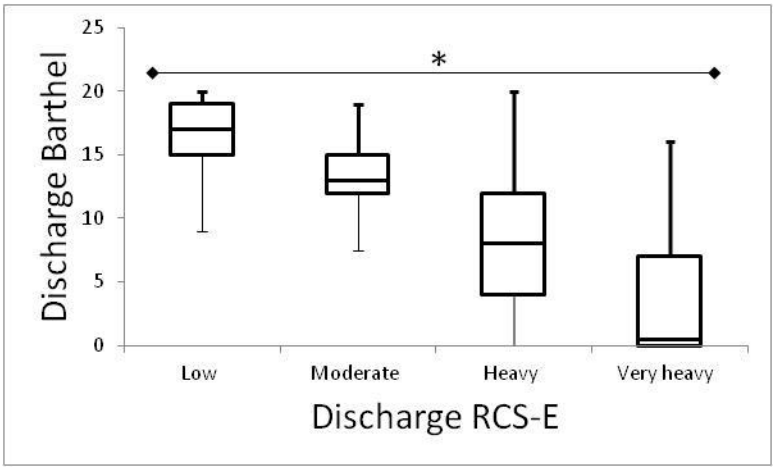


Figure 4.1 A & B. Box and whisper plots showing median, IQR and adjusted range for admission RCS-E and BI and admission RCSV2 and ISS. Kruskal-Wallis test was significant at p< 0.0001 across all RCS-E categories in relation to disability scores.

Figure 4.2A Admission rehabilitation complexity in relation to injury severity (ISS)

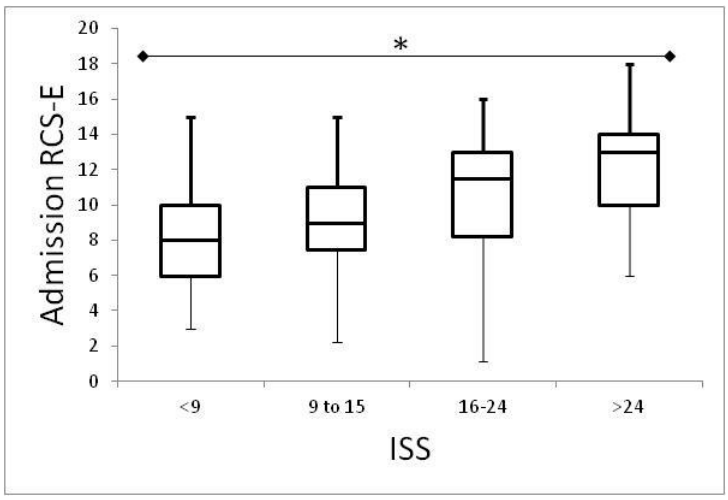


Figure 4.2B Admission rehabilitation complexity in relation to injury severity (ISS)

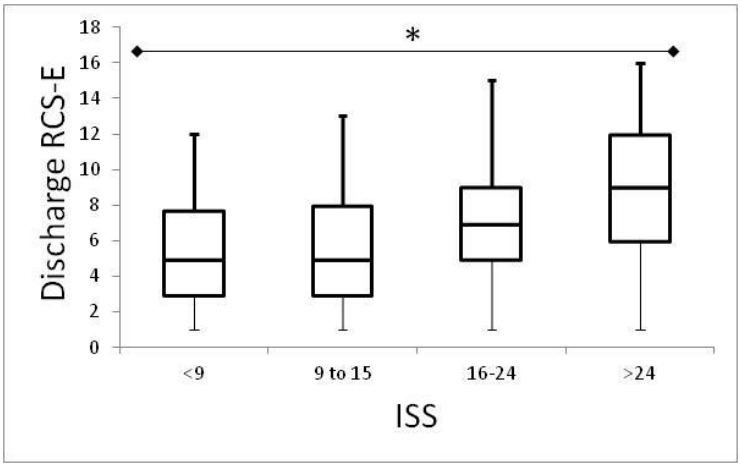


Figure 4.2 A & B. Box and whisper plots showing median, IQR and adjusted range for admission RCS-E and ISS. Kruskal-Wallis test was significant at p< 0.0001 across all RCS-E categories in relation to injury severity. (A & B) Rehabilitation needs has a moderate correlation with injury severity on admission (r=0.492) and discharge (r=0.4078).

There was a moderate correlation between injury severity and the RCS-E on admission (r=0.492, p<0.0001) and at discharge (r=0.4078). Severely injured patients (ISS≥16) had significantly higher RCS-E scores than patients with mild to moderate injuries (ISS<9:RCS-E 8 vs ISS≥16:RCS-E 12, p<0.0001 – Fig. 4.2A). However, there were notable differences between rehabilitation complexity and injury severity for a proportion of patients. 40% of patients with mild to moderate injuries (ISS<16) had 'Heavy' or 'Very Heavy' rehabilitation complexity (RCS-E score >10/20). Conversely, 24% of patients with 'low' or 'moderate' rehabilitation complexity (RCS-E score <10/20) were severely injured (Table 4.1; Figure

4.2A). The RCS-E is more specific at predicting rehabilitation need and rehabilitation complexity than the ISS. At discharge patients continued to have rehabilitation requirements despite their injury severity (Figure 4.2B)

Rehabilitation need and complexity for the majority of patients reduced from admission to discharge. Patients with low rehabilitation needs showed the smallest change where patients with high rehabilitation need the biggest change (Figure 4.3A). The change scores for each rehabilitation category were statistically significant ($p<0.0001$) (Figure 4.3B).

Figure 4.3A Improvement in rehabilitation from admission to discharge

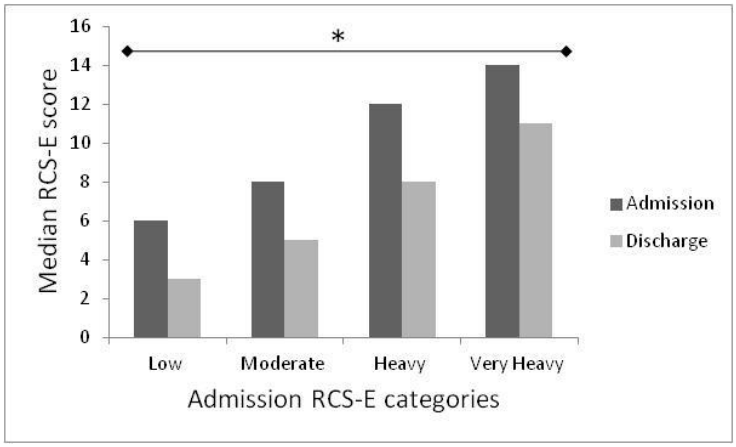


Figure 4.3A Bar chart demonstrating the median change in RCS-E scores for patients from admission to discharge. Wilcoxon signed-rank test is significant for same group comparison across all RCS-E categories ($p<0.0001$).

Figure 4.3B Improvement in rehabilitation from admission to discharge

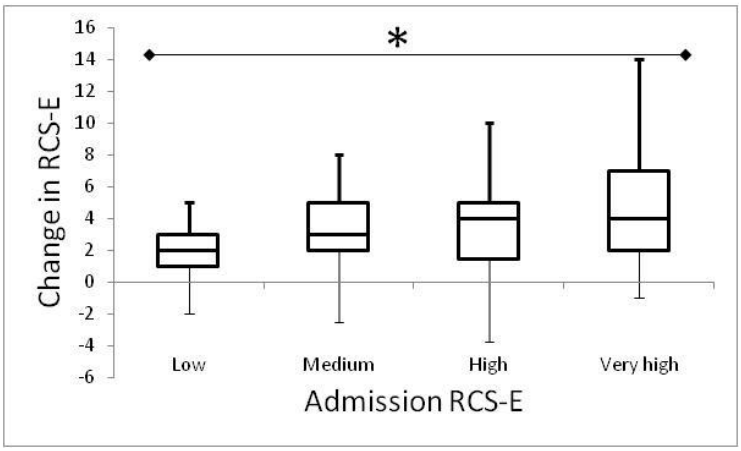


Figure 4.3B Box and whisper plots showing median, IQR and adjusted range for change of RCSV2 scores from admission to discharge. Kruskal-Wallis test significant across all RCSV2 categories p= 0.0005. The biggest change in rehabilitation need occurred in the very heavy RCS-E group.

Further clinical important outcomes related to discharge destination and length of stay. There was a moderate correlation between rehabilitation complexity and length of stay (LOS) (r=0.621, p<0.0001) (Figure 4.3C). Patients with low to moderate rehabilitation complexity had a median LOS of 5 days compared to heavy and very heavy rehabilitation categories with a median LOS of 17 and 28 days. The RCS-E was able to predict which patients are likely to need on-going rehabilitation (Figure 4.3D). Sixty percent of very heavy patients (RCS-E>13) were transferred for on-going rehabilitation, compared to only 9% of patients with low and moderate rehabilitation needs (RCS-E<10). Patients with a low RCS-E were more likely to be discharged home.

Figure 4.3C Rehabilitation complexity in relation to length-of-stay

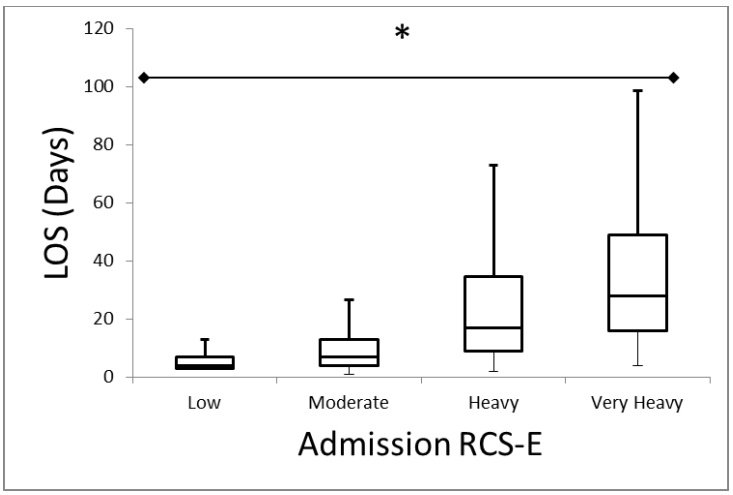


Figure 4.3C Box and whisper plots showing median, IQR and adjusted range for the relationship between RCS-E and length of stay. Length of stay increased with rehabilitation complexity. Kruskal-Wallis test was significant at p< 0.0001 across all RCS-E categories in relation to length of stay.

Figure 4.3D Rehabilitation complexity in relation to discharge destination

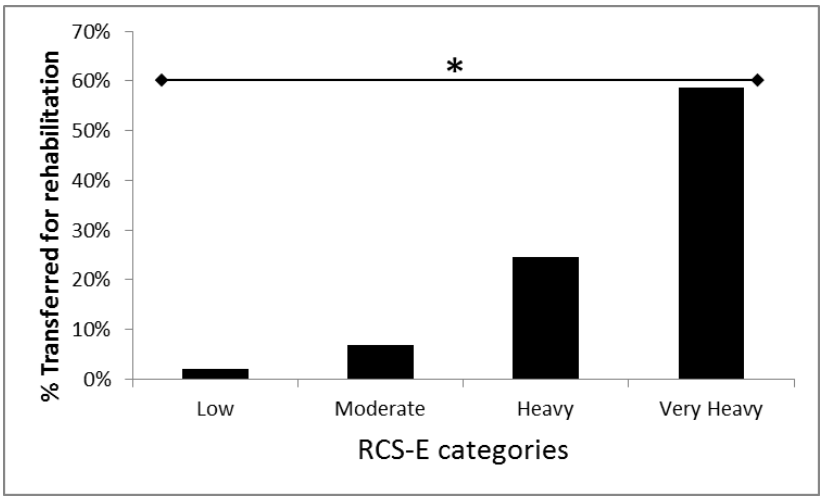


Figure 4.3D Bar chart for % patients transferred to rehabilitation in relation to admission RCS-E categories. Transfers to rehabilitation units increased as rehabilitation complexity increases. Chi Sq test significant at p< 0.0001 across all RCS-E categories in relation to discharge destination.

Table 4.2 Combined RCS-E categories and EuroQol levels in relation to separate EuroQol dimensions

	RCS-E Low EuroQol Level 1	RCS-E Moderate EuroQol Level 2	RCS-E Heavy EuroQol Level 3	p value
N=179 (%)	102 (57%)	49 (27%)	28 (16%)	
Discharge EQ-5D TTO values	0.32	0.27	0.18	p<0.02
3 Month EQ-5D TTO values	0.35	0.39	0.35	P=0.7463
Mobility (%)	47 (27%)	85 (48%)	45 (25%)	p<0.0001
Self-care (%)	67 (38%)	79 (45%)	31 (18%)	p<0.0001
Usual activities (%)	20 (11%)	54 (31%)	103 (58%)	p<0.0008
Pain or discomfort (%)	22 (12%)	114 (64%)	41 (23%)	p=0.4843
Anxiety or depression (%)	76 (43%)	72 (41%)	29 (16%)	p<0.0380
Overall Health (%)*	100 (56%)	49 (28%)	28 (16%)	p=0.1613

*Overall health measured by the visual analogue scale (VAS) where 100 is the best possible health and 0 the worst possible health.

Table 4.2 Discharge RCS-E categories combined with EuroQol categories in relation to separate EuroQol dimensions. Quality of life reduces as rehabilitation complexity increase.

EuroQol data was collected for 179 (57%) patients (Table 4.2). No QOL scores were collected for patients with very high rehabilitation complexity (RCS-E 14-20), although this was unintentionally. There was a weak negative correlation between discharge RCS-E scores and QOL data quantified with TTO values (r=-0.0358, p=0.0015). QOL decreased as rehabilitation complexity increased with a statistically significant difference between rehabilitation categories and EuroQol values (p<0.02) (Figure 4.4A). Patients with low rehabilitation complexity had better QOL although still significantly below population norms (Figure 4.4A). Between group comparison for QOL at three months was not significant (p=0.7463) despite significant QOL improvements for patients in low (p<0.0062) and moderate (p<0.019) rehabilitation categories (Figure 4.4B).

Figure 4.4A Rehabilitation complexity in relation to quality of life measured with the EuroQol

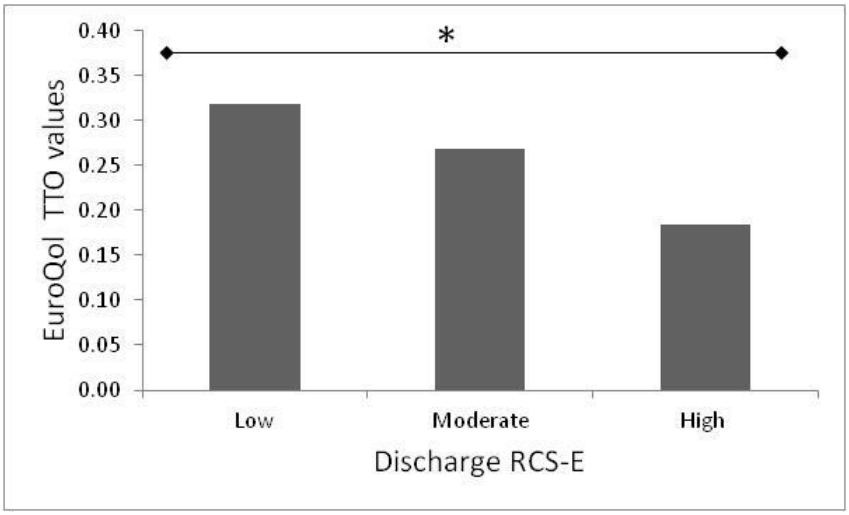


Figure 4.4A Bar chart showing decreasing EuroQol time trade of (TTO) values in relation to discharge RCS-E categories. Smaller TTO values indicate worse quality of life. Kruskal-Wallis test significant across all RCS-E categories p=0.0204.

Figure 4.4B Rehabilitation complexity in relation to 3-month post discharge quality of life data

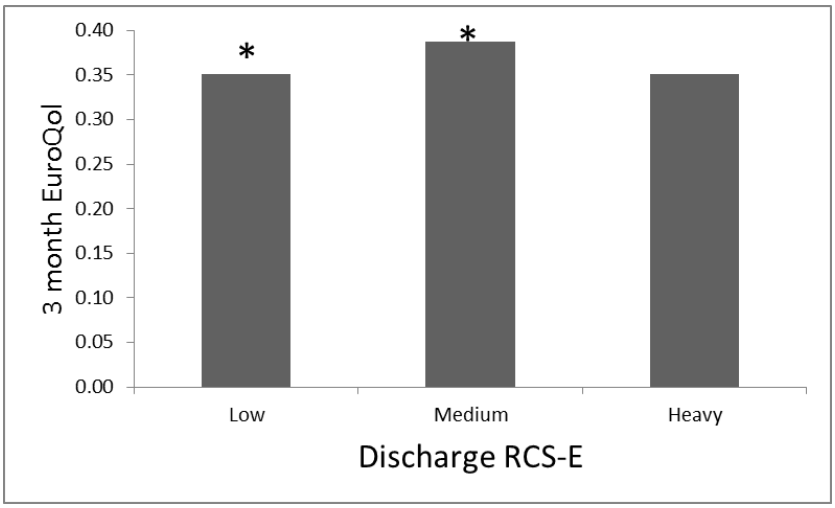


Figure 4.4B Bar chart showing EuroQol TTO values three months post injury in relation to RCS-E categories. Wilcoxon signed-rank test is significant for same group comparison shows a statistically significant difference between admission and three month TTO values for patients in the low ($p<0.0062$) and moderate ($p<0.019$) rehabilitation categories. Kruskal-Wallis test across RCS-E categories were not significant at $p=0.7463$.

Further analysis examined the relationship between the five separate EuroQol dimensions and rehabilitation complexity categories. Each EuroQol dimension has three response options. Level 1=No problem/ Independent, Level 2=Some problems/ Moderate dependence and Level 3=Unable to do/ Dependent. There was a surprisingly strong association between rehabilitation need and four of the five categories. As rehabilitation complexity increased, level of dependence, represented by the three EuroQol levels increase for mobility, self-care, usual activities and anxiety or depression (Figure 4.5A-4.5D; $p<0.0001$). This relationship was not seen for 'pain and discomfort' (Figure 4.5E, $p=0.4843$) or general health measured with the visual analogue scale (Figure4.4.5F, $p=0.1613$). There seems to be an association between rehabilitation complexity and reduced levels of function and dependence as categorised by the EuroQol levels although a poor association with more subjective dimensions such as pain or general health.

Figure 4.5A Relationship between rehabilitation complexity and EuroQol mobility dimension

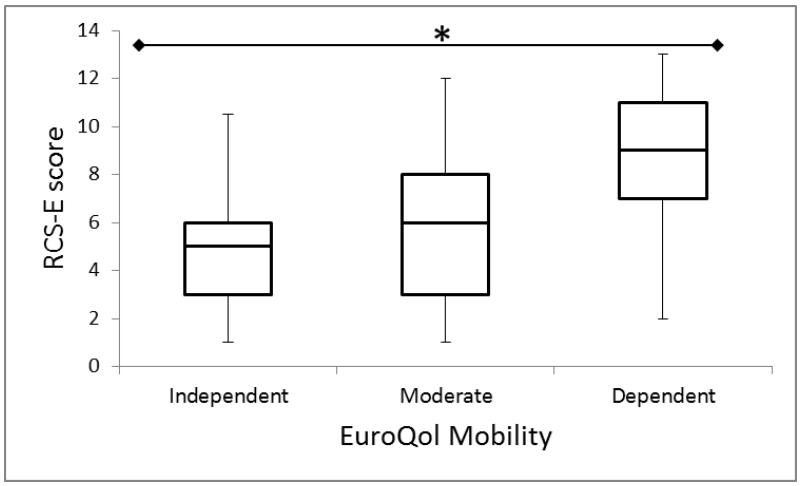


Figure 4.5B Relationship between rehabilitation complexity and EuroQol self-care dimension

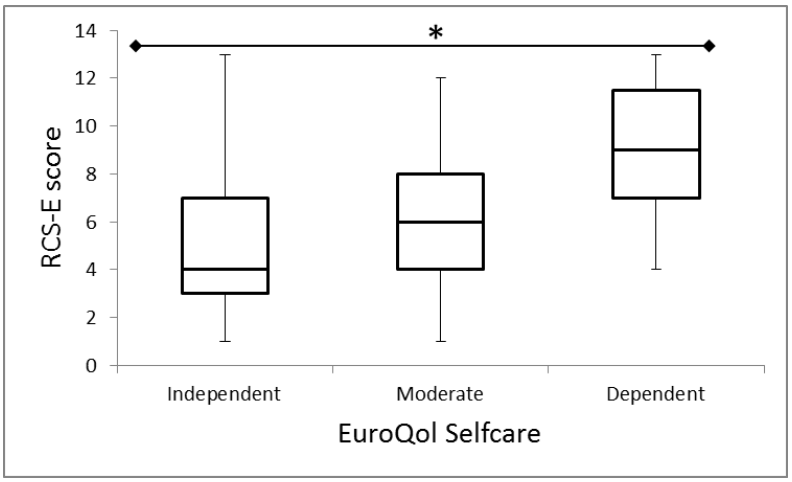


Figure 4.5C Relationship between rehabilitation complexity and EuroQol usual activities

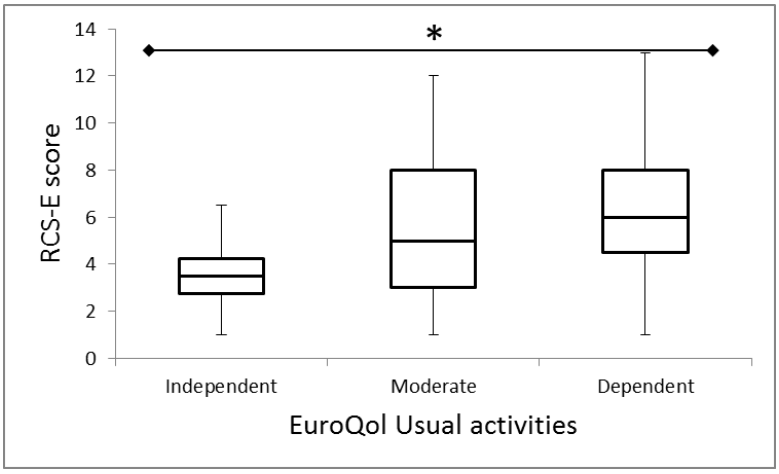
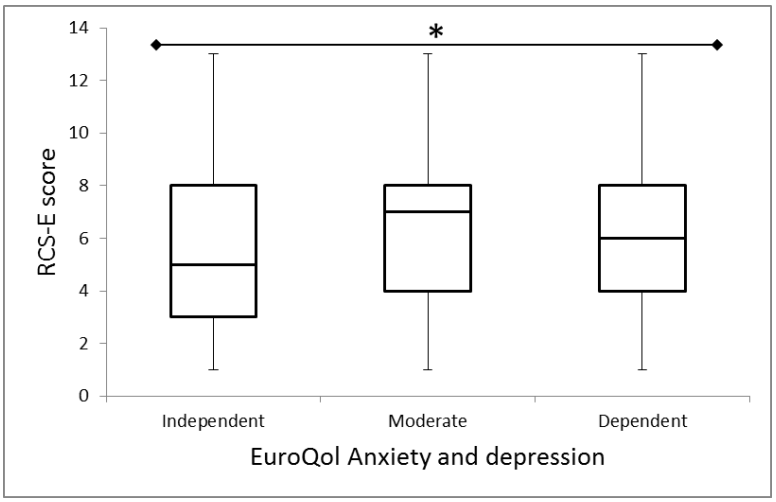


Figure 4.5D Relationship between rehabilitation complexity and EuroQol anxiety and depression



Figures 4.5A-D Box and whisper plots showing median, IQR and adjusted range across all RCS-E categories in relation to EuroQol dimensions of mobility, self-care, usual activities, anxiety and depression. Kruskal-Wallis test was significant at p< 0.0001 across all RCS-E categories in relation to EuroQol categories of mobility, self-care, usual activities and anxiety and depression (A-D).

Figure 4.5E Relationship between rehabilitation complexity and EuroQol pain and discomfort

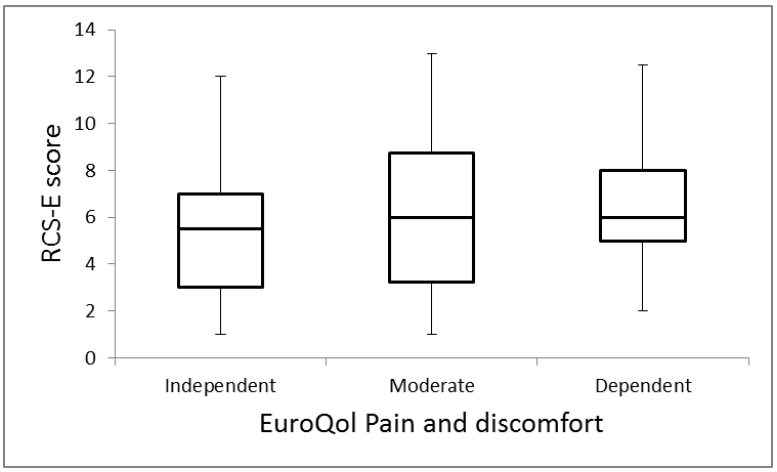


Figure 4.5E Box and whisper plots showing median, IQR and adjusted range across all RCS-E categories in relation to EuroQol pain dimension. Kruskal-Wallis test was not significant at p=0.4843.

Figure 4.5F Relationship between EuroQol general health and rehabilitation complexity

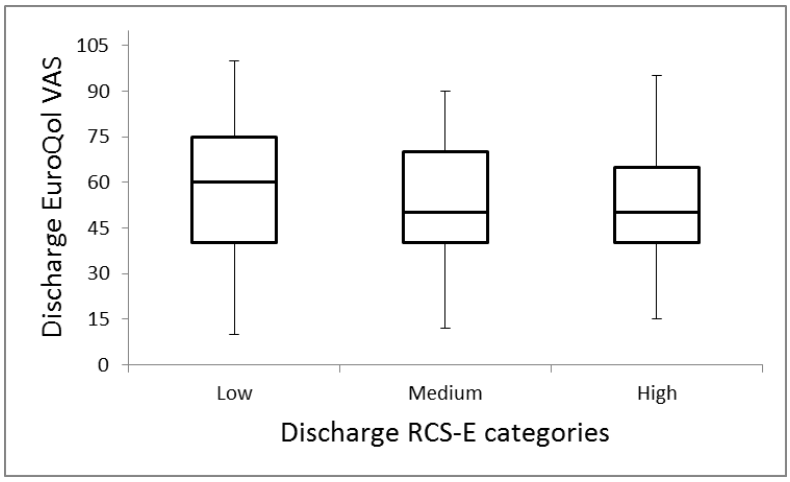


Figure 4.5F Box and whisper plots showing median, IQR and adjusted range for discharge EuroQol visual analogue scores (VAS) in relation to RCS-E categories. A higher VAS indicated better overall health. (P=0.1613).

4.4 Discussion

This study demonstrates the important relationship between rehabilitation complexity of trauma patients and outcomes. The RCS-E is able to prospectively characterize rehabilitation requirements for patients with traumatic injuries, is more accurate than existing measures and supports findings from the pilot study (419). These findings contribute to the evidence required to support acute rehabilitation and justify related costs (197).

It is recognised that over time and with effective rehabilitation, patient's needs may vary and will often reduce over time in both amount and complexity (240, 420). Effective rehabilitation could manage people with a range of problems and distribute therapy resources appropriately through frequent re-evaluation of patient rehabilitation requirements (421). This will not only ensure cost effectiveness (422) and appropriate resource allocation (405, 423) but also timely intervention to ensure optimal patient recovery (424, 425). This study data demonstrates that the RCS-E can measure rehabilitation needs in an acute hospital setting and that rehabilitation requirements do change over time. Not only do less severely injured patients require rehabilitation on admission, they continue to require rehabilitation on discharge. The RCS-E quantifies the amount and the type of rehabilitation required better than traditional measures such as injury severity score (ISS) or disability measures (BI). Admission BI scores had a flooring

effect where 37% of patients were completely dependent (0/20). Patients changed on average one category on the RCS-E compared to two on the BI suggesting the RCS-E is responsive to change without a ceiling effect like the BI.

Patients continue to have rehabilitation requirements on discharge despite becoming more independent, measured with the BI. An improvement in independence does not necessarily correlate to complete recovery to previous health (123, 426, 427). For example a patient with bilateral lower limb amputations will have an ISS of 9. They could score 16/20 on the BI, only requiring minimal assistance in hospital despite significant ongoing rehabilitation requirements.

Traditionally, trauma patients are divided into minor (ISS<16) and major trauma (ISS≥16) in terms of injury severity (3, 63). These categories are often used to predict patient outcome or classify funding streams which is the current approach in the UK (428). In addition, prediction models have been developed to calculate morbidity and cost in terms of hospital length of stay and discharge destination (429). While these models are helpful, much of this data such as the ISS or other anatomical scoring systems are not readily available to rehabilitation professionals in an acute care setting which limits the application of the model. A more appropriate, independent scoring system based on rehabilitation complexity, rather than diagnosis is required (228, 430, 431). This data demonstrates that the RCS-E is responsive over time. Additionally, it has the potential to predict outcome such as length of stay and discharge destination without the application of a complicated model. The RCS-E provides more information on rehabilitation needs and acute hospital outcomes, such as discharge destination and LOS than traditional tools. The RCS-E shows potential use in categorising rehabilitation complexity of trauma patients. Patient complexity could be utilised in trauma service and system development to ensure resource-efficient rehabilitation services and patient outcome.

Compared to the general population, trauma patients continue to suffer reduced QOL up to two years after injury (61, 432). Many different reasons are attributed to this, including injury severity, age, sex and education (433-435). However, this study is the first to look at the relationship between acute rehabilitation needs and QOL, measured with the EuroQol. The EuroQol is frequently used in trauma outcome studies (127, 347) and guideline documents has recommended its' use (161). The strong association between discharge rehabilitation complexity and QOL, although not statistically correlated, suggests that

individuals continue to have health and rehabilitation needs at discharge despite improvements in independence. This relationship between health outcome (QOL) and rehabilitation needs, demonstrated in this study, shows promising potential of the predictive properties of the RCS-E in acute trauma settings in terms of QOL and potentially long term health outcome. The application of one tool, applied consistently across trauma patient populations will not only assist in improved service structures but also ensure timely and appropriate interventions to improve patient perceived health outcome.

Limitations

This study has several limitations. Firstly, many patients had admission scores (n=458) but only 67% (n=307) had complete data sets for RCS-E, ISS and BI. Although this is a larger sample size than the pilot study the figures are disappointing. Adequate data collection was restricted by the availability of only one clinician collecting patient outcome twice a week with a high patient turnover in the trauma service. Secondly, only a small proportion (57%) of QOL data was collected and no data was available for patients with very complex rehabilitation needs (RCS-E 14-20). This led to an under representation of patients with complex rehabilitation need. Due to the small sample of QOL data available, further analysis is required to confirm the predictive properties of the RCS-E in terms of QOL.

The study sample was representative of one trauma centre which potentially limits opportunities to generalise results. However, the patient population was representative of an urban trauma centre found in the UK and other European countries. Finally, I did not measure the amount of rehabilitation input that patients received whilst in hospital. This information could be useful for further analysis of the accuracy of the RCS-E in terms of rehabilitation intensity and complexity to identify clinically important discrepancies between rehabilitation needs and the provision of rehabilitation services.

Conclusions

The RCS-E should be considered for use in acute trauma care to more accurately define rehabilitation requirements. The data demonstrates that a complexity driven, rather than diagnostic driven classification can assist in anticipating length of stay and rehabilitation referrals and thus enable improved resource management. While the relationship with the EuroQol requires further exploration, the data suggests that rehabilitation requirements could reflect functional components of QOL. The ease of application of the RCS-E in a busy clinical setting will enable consistent re-evaluation of patient need which could lead to

clinical improvements and trauma system effectiveness. In spite of this, more needs to be done to capture the full extent of health outcome after trauma and not just rehabilitation complexity or requirements. The application of a framework, such as the ICF, could aid in improved health outcome assessment as it contains many other important health categories including environmental factors and access to services. In recognition of this, the next chapter will systematically review the comprehensiveness of measures used in trauma outcome studies within the framework of the ICF.

Chapter 5: COMPREHENSIVENESS OF EXISTING OUTCOME MEASURES USED TO EVALUATE HEALTH OUTOCME IN MAJOR TRAUMA

5.1 Introduction

The previous chapter discussed the importance of acute rehabilitation and established that the RCS-E can be used to measure rehabilitation complexity in trauma patients. The application of appropriate measures in an opportune timeframe is necessary to evaluate patient outcomes and trauma system effectiveness. Precise outcome measurement can be very complex due to the heterogeneity of injuries seen in trauma patients. While there are several measures that evaluate outcome and QOL following trauma (436) it is not clear to what extent they are able to capture the full range of effects injury may have on health and well-being. Generic measures are used to assess recovery after trauma (61, 168, 437, 438). However, there are no studies that examine how well these capture the full range of health impacts that trauma patients may experience.

The comprehensive measurement of function, disability and health outcomes after injury is of fundamental importance to trauma care. Understanding the full extent of the impact of trauma on an individual's health has the potential to direct treatment, rehabilitation and social care services (197). Capturing health impact on a population basis is important for health services design and delivery, resource allocation and for future research and development (150).

The ICF has been successfully applied in other diseases and health care systems to standardise health outcome assessment, measure population health and develop services (103-107). ICF is discussed in more detail in the introduction of this thesis. The primary aim of this study is to evaluate the comprehensiveness of measures frequently used in trauma outcome studies. In particular I examined to what extent health concepts are represented within these instruments using the ICF as a reference.

5.2 Methods

5.2.1 Study design

A systematic review of outcomes measures frequently used in trauma studies using the ICF as a reference.

5.2.2 Data collection and data extraction

More detail on the study selection, search strategy (Appendix 8) and exclusion criteria can be found in chapter 2, section 2.5.2 of this thesis. Studies published between 2006 and inclusive of 2012 were included specifically to investigate the application of the ICF in outcome measures used in trauma research. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis process (PRISMA) (353) was used to identify suitable studies. Included studies focused on function and disability after multiple traumatic injuries rather than single system injuries. The study selection process is summarized in Figure 5.1.

Screening and data extraction is also discussed in more detail in section 2.5.2. All study titles and abstracts, including reference lists were screened by two independent researchers Karen Hoffman (KH) and Elaine Cole (EC) and studies were selected for inclusion as described previously. Any discrepancies were resolved by both researchers re-reviewing the study. The information extracted from studies included: Country of publication, study design, sample size and outcome measures used (Table 5.1, Table 5.2 and Appendix 5). In a second step outcome measures that occurred in at least three or more studies or those which are valid, trauma specific outcome measures were identified for ICF content analysis.

5.2.3 Data analysis

The GRADE methodology (Grading quality of evidence and strength of recommendations) was used to judge the quality of the evidence of included studies (354-357). The overall methodological quality of combined studies is not discussed in detail as it was not relevant to the primary aim of this study although it was important to evaluate the quality of the research at the time of the study.

Outcome measures that occurred in at least three or more studies or those which are valid, trauma specific outcome measures were identified for ICF content analysis. The established ICF linking process was used to link concepts contained in measures to the ICF.

Linking methodology was discussed previously in detail in section 2.4.1 in the methods chapter. The primary researcher linked all identified measures to the ICF. A random selection of forty percent of concepts were also linked and compared by a second researcher (EC) to reduce researcher bias and ensure data accuracy. Linked data were compared to ICF linking results of similar measures if these occurred in other ICF publications (172, 358, 359). This was used to check validity and accuracy of linking results where appropriate. Where items were linked to the third- and fourth-level categories they were aggregated to second level categories.

In a second step frequency analysis was carried out to examine the most frequently represented ICF categories contained in outcome measures. This is determined by calculating absolute and relative frequencies of all ICF categories identified in measures to define how often an ICF category is captured overall in measures used in trauma research. Frequency analysis is discussed in more detail in section 2.4.2. ICF categories which had a relative frequency of 30% were regarded as frequently used categories. The full data set for all ICF categories linked to measures is presented in Appendix 9.

ICF representation in terms of to what degree measures coved concepts contained in the ICF was calculated using content density, bandwidth and content diversity. This is useful to establish the breadth, depth and diversity of outcome measures in relation to the ICF (358). These methods are described in detail in section 2.5.3. However, Table 5.1 provides a summary of these analyses for reference purposes.

Table 5.1 Overview of analysis used to examine ICF representation in outcome measures

Content density evaluates the ratio of the number of ICF categories contained per instrument in relation to the number of items in the instrument. Measures with smaller content density have fewer and less complex items, which makes these easier to use in clinical settings (360). A content density of one indicates that each item in the measures represents one ICF category. Greater than one indicates that each item measures more than one ICF category, thus more questions evaluating the same concept and a longer questionnaire.
Content diversity measures the depth or detail of the instrument. A lower content diversity indicates that several items and their concepts are dedicated to measure the same topic or ICF category (360). Thus a measure could have 8 questions where five items relate to mobility and three items relate to self-care. This measure will have a low content diversity as it only measures two concepts. Measures with a greater content diversity measures more ICF categories.
Bandwidth, reported as a percentage (%) measures the breadth of the instrument. It calculates the percentage of ICF categories in each instrument in relation to the total number of ICF categories (1454 categories). As I focused on second level categories, I calculated bandwidth using 363, the total number of second level categories rather than all 1454 ICF categories. A larger bandwidth (%) indicates that a greater number of ICF categories are included in the instrument, thus greater ICF coverage.

Table 5.1 Content density, bandwidth and content diversity of measures were calculated to establish the breadth, depth and diversity of outcome measures in relation to the ICF

5.3 Results

The search identified 755 published articles. After duplicates were removed, 665 articles were excluded following abstract review. A full text review of 54 articles led to the final inclusion of 34 articles (Figure 5.1). Excluded studies consisted of twelve that did not measure health outcome, six evaluated outcome of a single system rather than multiple injuries and two studies evaluated health care resource use rather than outcome. Two research groups reported results on the same cohort of patients at different times from injury in four studies (61, 437, 439, 440). The cohort size decreased over time due to loss to follow up. Data on all four of these studies were included.

Figure 5.1 PRISMA flow diagram of the screened and included papers

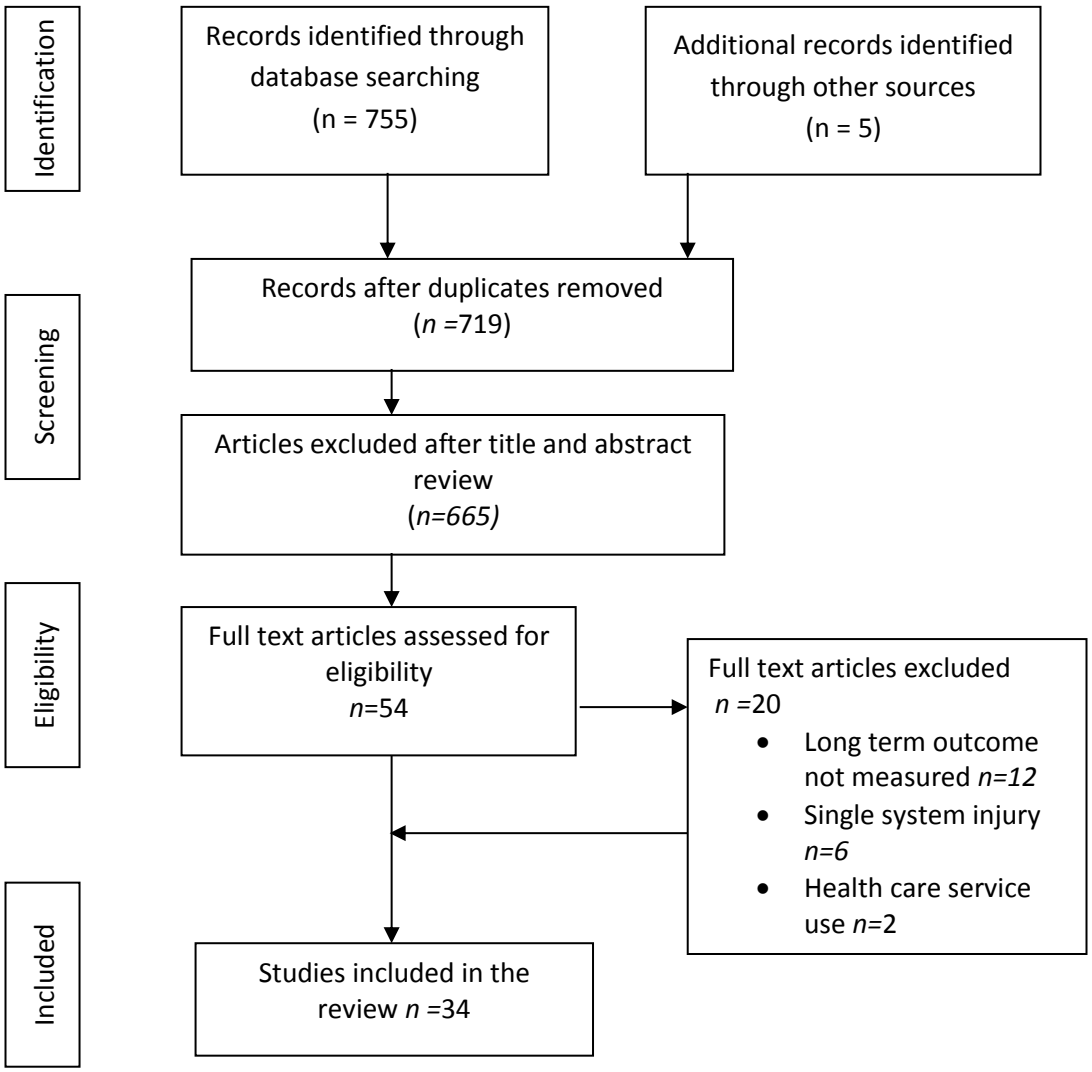


Figure 5.1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram of screened and included papers

5.3.1 Study characteristics

Two studies were graded as moderate quality of evidence (73, 383), twenty nine studies were low, and one very low (171) quality evidence. The overall qualitative characteristics and GRADE quality review of the studies are presented in Appendix 5.

Three of the 34 studies were RCT's, involving 1086 participants (73, 441, 442). One described a specific rehabilitation intervention using cognitive behavioural therapy to reduce post-traumatic stress and improve quality of life (441); the other study, evaluated the impact of recombinant Factor VII on long term health outcome after severe trauma (73). The largest RCT (n=568) evaluated the cost effectiveness of a nurse led telephone follow-up to improve quality of life for discharged trauma patients. There were 26 prospective cohort studies involving a total of 12664 participants. The remainder were retrospective studies (n=6751). Collectively the studies were conducted in different countries and continents: Seven in the USA (171, 387, 443-447); six in Australasia (four in Australia and two in New Zealand) (74, 384, 385, 435, 448, 449); 19 in Europe (five in Germany (433, 441, 450-452), four each in The Netherlands (33, 63, 71, 383) and Norway (54, 61, 437, 453), two each in the UK (439, 440) and Sweden (442, 454), one each in Switzerland (455), Denmark (73) and one each in Israel (170) and South Africa (456) (Table 5.2 and Appendix 5).

Table 5.2. Characteristics of studies included in the review

Source	Study design	Number of participants	Country	Standardised outcome instruments
Ballabeni et al, 2011 (455)	Prospective cohort	391	Switzerland	Karasek's 31-item Job Content Questionnaire (JCQ)
Baranyi et al, 2010 (452)	Prospective cohort	52	Germany	German version of the Clinician-Administered PTSD Scale (CAPS) Syndrom-Kurz Test (SKT) Beck Depression Inventory (BDI), Impact of Events Sale (IES) Dissociative Experience Scale (DES) Medical Outcomes Study Short Form Health Survey (SF-36)
Christensen et al, 2011 (73)	RCT	347	Denmark	Polytrauma Outcome Chart consisting of the - Glasgow Outcome Scale (GOC) European Quality of Life Questionnaire (EuroQol) SF-36 Trauma Outcome Profile (TOP)
Derrett et al, 2010 (449)	Prospective cohort	111	New Zealand	World Health Organisation Disability Assessment Schedule II (WHODAS II) EuroQol
Franzén et al, 2009 (442)	RCT	568	Sweden	EuroQol
Gabbe et al, 2013 (384)	Prospective cohort	617	Australia	Study Short Form 12 (SF-12) Glasgow Outcome Scale-Extended (GOS-E)
Gabbe et al, 2012 (435)	Database review	4986	Australia	GOS-E
Gabbe et al, 2006 (448)	Prospective cohort	662	Australia	Modified Functional Independence Measure (FIM)
Harris et al, 2008 (74)	Prospective cohort	355	Australia	SF-36
Holtslag et al, 2007 (63)	Prospective cohort	335	The Netherlands	Glasgow Outcome Scale (GOS) EuroQol Head injury symptom checklist (HISC)
Holtslag et al, 2006 (33)	Prospective cohort	186	The Netherlands	Glasgow Outcome Scale (GOS) Groningen Activity Restriction Score (GARS) Sickness Impact Profile-136 (SIP) SF-36

Source	Study design	Number of participants	Country	Standardised outcome instruments
Jackson et al, 2007 (444)	Prospective cohort	58	USA	Informant Questionnaire of Cognitive Decline in the Elderly-Short Form (IQCODE-SF) SF-36 Beck's Depression Inventory (BDI) Katz Index of Independence in Activities of Daily Living Davidson Trauma Scale (DTS) Beck's Anxiety Inventory Functional Activities Questionnaire ((FAQ) Awareness questionnaire
Kiely et al, 2006 (445)	Prospective cohort	123	USA	SF-36 FIM Post-Traumatic Stress Disorder Checklist (PCL) Centre for Epidemiologic Studies Depression Scale (CES-D-10)
Langley et al, 2011 (385)	Prospective cohort	2856	New Zealand	EQ-5D
Livingston et al, 2009 (446)	Prospective cohort	100	USA	GOS FIM Modified FIM
Mackenzie et al, 2008 (447)	Retrospective cohort	1389	USA	Musculoskeletal Function Assessment (MFA) –mobility subscale Centre for Epidémiologique Studies Depression Scale (CESD-R) SF-36
Orwelius et al, 2012 (454)	Prospective cohort	108	Sweden	SF-36
Pape et al, 2010 (433)	Prospective cohort	637	Germany	SF-12, Hannover Score for Poly-trauma Outcome (HASPOC)
Pirente et al, 2007 (441)	RCT	171	Germany	Beck's Depression Inventory (BDI) SF-36 State-Trait Anxiety Inventory (STAI) Symptom Checklist 90-Revised (SCL 90R) Social support Questionnaire (Fragebogen zur Sozialen Unterstützung; F-SOZU-22)

Source	Study design	Number of participants	Country	Standardised outcome instruments
Polinder et al, 2007 (71)	Prospective cohort	3231	The Netherlands	EuroQol
Probst et al, 2010 (450)	Prospective cohort	637	Germany	Hannover Score for Poly-trauma Outcome Short form-12, HADS
Ringburg et al, 2011 (383)	Prospective cohort	246	The Netherlands	Health Utilities Index (HUI) EuroQol
Sayer et al, 2008 (387)	Retrospective cohort	188	USA	Functional Independence Measure (FIM)
Schwartz et al, 2007 (170)	Retrospective cohort	72	Israel	Functional Independence Measure (FIM) Impact of Events Scale (IES)
Siddharthan et al, 2008 (171)	Retrospective cohort	116	USA	FIM
Soberg et al, 2007 (453)	Prospective cohort	100	Norway	Brief Approach/Avoidance Coping Questionnaire Multidimensional Health Locus of Control Short Form-36 WHODAS-ll
Soberg et al, 2007 (61)	Prospective cohort	105	Norway	Short Form (SF)-36 WHODAS II
Soberg et al, 2010 (54)	Prospective cohort	99	Norway	SF-36 Post-Traumatic Symptom Scale 10 (PTSS-10)
Soberg et al, 2012 (437)	Prospective cohort	105	Norway	SF-36 WHODAS II
Steel et al, 2010 (443)	Prospective cohort	620	USA	SF-12
Sutherland et al, 2006 (439)	Prospective cohort	200	UK	General Health Questionnaire (GHQ) Sickness Impact Profile (SIP) Musculoskeletal Function Assessment (MFA) SF-36

Source	Study design	Number of participants	Country	Standardised outcome instruments
Sutherland et al, 2011 (440)	Prospective cohort	104	UK	General Health Questionnaire (GHQ) Sickness Impact Profile (SIP) Musculoskeletal Function Assessment (MFA) SF-36
Van Aswegen et al, 2011 (456)	Prospective cohort	42	South Africa	SF-36
Zeckey et al, 2011 (451)	Prospective cohort	620	Germany	HASPOC SF-12 Glasgow Outcome Scale (GOS)

5.3.2 Description of outcome measures

Thirty eight outcome measures were identified in 34 studies (Table 5.3). Twenty one outcome measures were used only once. Five outcome measures were used in three or more studies and two trauma specific tools were used in less than three studies. The most frequently used outcome measure was the Medical Outcome Study Short Form Health Survey (SF-36) (128) used in 14 studies. The other four generic outcome measures were the European Quality of Life Questionnaire (EuroQol)(126), used in seven studies; the Functional Independence Measure (FIM) (155) and the Glasgow Outcome Scale (GOS) (129) both used in 5 studies; and the World Health Organisation Disability Assessment Schedule (WHODAS ll) (265) used in four studies (Table 5.2 and Table 5.3). There were only two trauma-specific tools. The Hannover Score for Polytrauma Outcome (HASPOC) (457) was used in 3 studies and the Trauma Outcomes Profile (TOP)(458) in one study. The HASPOC was only used in Germany. I was unable to find an example of the HASPOC or information on the psychometric properties of this instrument. Therefore this instrument was excluded from ICF linking. Literature pertaining to the development and psychometric properties of the TOP are limited although a recent study concluded that the TOP has potential use in trauma populations but requires further validation (458). Five generic and one trauma specific outcome measures were included in the analysis based on the inclusion criteria.

Table 5.3. Overview of the thirty eight outcome measures identified in 34 studies

Description of instruments	n	% of 34 studies
Medical Outcome Study Short Form Health Survey (SF-36)	14	41
European Quality of Life Questionnaire (EuroQol)	7	21
Functional Independence Measure (FIM)	5	15
Glasgow Outcome Scale (GOS)	5	15
World Health Organisation Disability Assessment Schedule II (WHODAS II)	4	12
Hannover Score for Polytrauma Outcome (HASPOC)	3	9
Musculoskeletal Function Assessment (MFA)	3	9
Medical Outcome Study Study Short Form 12 (SF-12)	3	9
Sickness Impact Profile (SIP)	3	9
Glasgow Outcome Scale-Extended (GOS-E)	2	6
Modified Functional Independence Measure (FIM)	2	6
Impact of Events Scale-Revised (IES-R)	2	6
Social Support Questionnaire (SSQ)	2	6
Beck's Depression Inventory (BDI)	2	6
General Health Questionnaire (GHQ)	2	6
Centre for Epidemiologic Studies Depression Scale (CES-D)	2	6
Awareness questionnaire	1	3
Beck's Anxiety Inventory	1	3
Brief Approach/Avoidance Coping Questionnaire	1	3
Davidson Trauma Scale (DTS)	1	3
Dissociative Experience Scale (DES)	1	3
Functional Activities Questionnaire (FAQ)	1	3
German version of the Clinician-Administered PTSD Scale (CAPS)	1	3
Groningen Activity Restriction Score (GARS)	1	3
Health Utilities Index (HUI)	1	3
Hospital Anxiety and Depression Scale (HADS)	1	3
Informant Questionnaire of Cognitive Decline in the Elderly-Short Form (IQCODE-SF)	1	3
Karasek's 31-item Job Content Questionnaire (JCQ)	1	3
Katz Index of Independence in Activities of Daily Living	1	3
Multidimensional Health Locus of Control	1	3
Post Traumatic Symptom Scale (PTSS-10)	1	3
Post-Traumatic Stress Disorder Checklist (PCL)	1	3
Social support Questionnaire (Fragebogen zur Sozialen Unterstützung; F-SOZU-22)	1	3
State-Trait Anxiety Inventory (STAI)	1	3
Symptom Checklist 90-Revised (SCL 90R)	1	3
Syndrom-Kurtz Test (SKT)	1	3
Trauma Outcomes Profile (TOP)	1	3

5.3.3 Degree to which measures cover concepts contained in the ICF

Overall 250 meaningful concepts were identified across 132 items (questions) within six outcome measures (Appendix 9). The TOP captured the most meaningful concepts (n=107), whilst the rest were distributed across the SF-36 (n=53), FIM (n=37), WHODAS ll (n=34), EuroQol (n=10) and the GOS (n=9). These 250 meaningful concepts were linked to 86 of a possible 363 second level categories (24%), and represented only 6% of the total number of ICF categories (n=1454) (Figure 5.2).

Figure 5.2 ICF framework and total number of second level ICF categories identified in six outcome measures

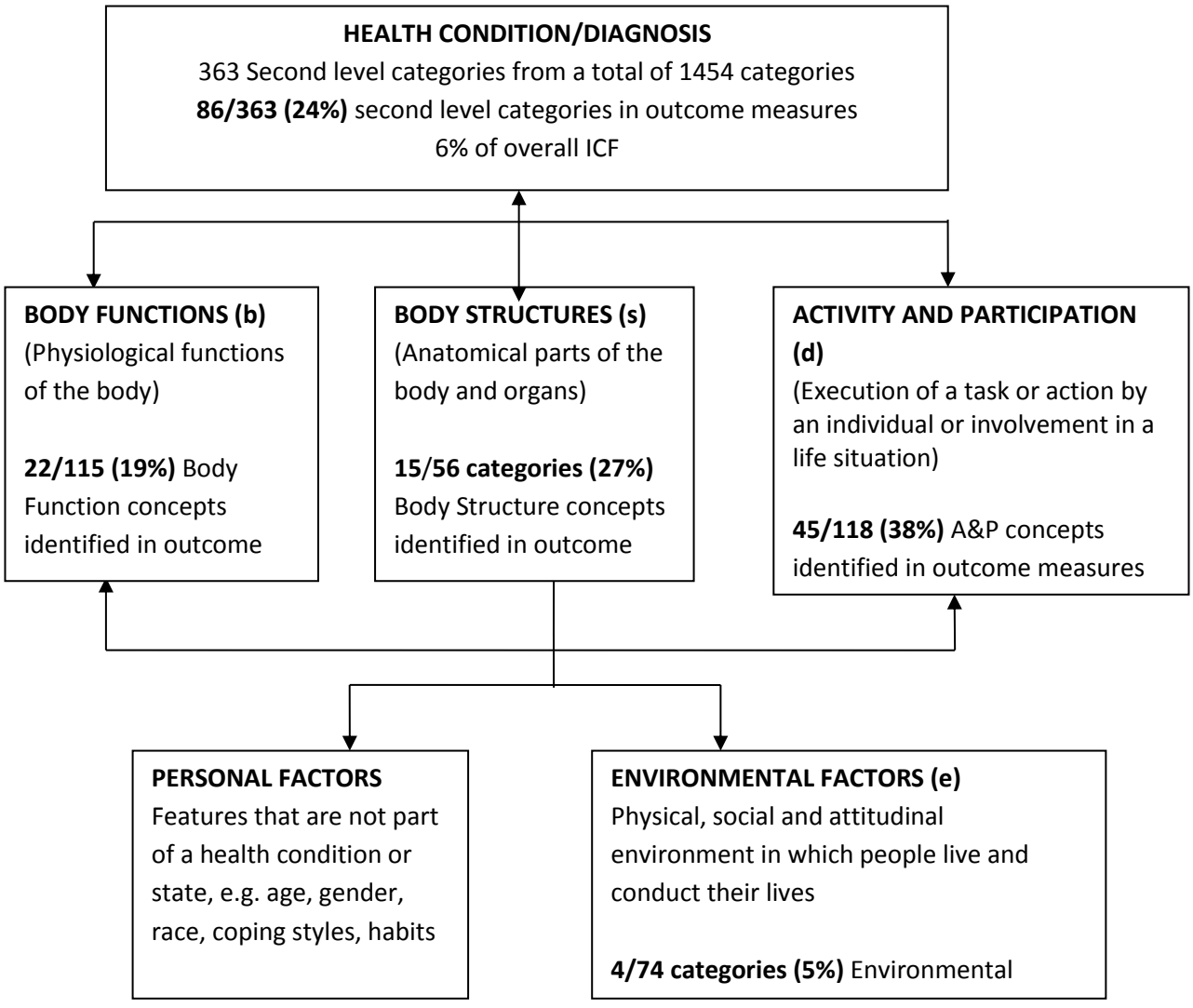


Figure 5.2 ICF framework illustrating four different components body function (b), body structure (s), activity and participation (d) and environmental factors (e). Personal factors currently do not have categories and codes. Numbers and percentages indicate total number of second level categories linked to each component and overall ICF representation.

Table 5.4 summarises the content analysis of the individual measures. Bandwidth was calculated in relation to 363 second level categories, rather than all 1454 ICF categories. The SF-36 was used approximately three times more (14 citations) than the other generic measures but represents a small proportion of the ICF (bandwidth of 6.3%). Items were linked to nine of the thirty ICF chapters (30%): two in the *body function* (b) component and seventeen in the *activity and participation* (d) component. The small content diversity (0.43) reflects the depth of the measure (several items and their concepts are dedicated to measure the same topic or ICF category).

Table 5.4 Content analysis of measures and individual ICF representation

	SF-36	EuroQol	FIM	GOS	WHODAS II	TOP
Number of studies cited in	14	7	5	5	4	1
Number of items in measure	36	5	18	5	36	32
Total concepts per measure	53	10	37	9	34	107
ICF categories	23	10	29	9	24	61
Body Function	6	2	10	2	3	14
Body Structure	0	0	0	1	0	14
Activity and Participation	17	8	19	6	21	29
Environmental factors	0	0	0	0	0	4
Content density*	0.64	2.0	1.61	1.8	0.67	1.91
Bandwidth (%) **	6.3	2.8	8.0	2.5	6.6	16.8
Content diversity †	0.43	1.0	0.78	1.0	0.71	0.57

* Content density – number of ICF categories/ number items in an instrument

** Bandwidth (%) - number of distinct ICF categories/total number of second level ICF categories (363) x100%

† Content diversity - total number of different ICF categories/ number of meaningful concepts in the instrument

Table 5.4 Content analysis of individual measures indicate a small ICF representation (bandwidth %). Environmental factors are only represented in one measure (TOP). The concepts contained in the TOP was also linked to the most ICF categories (n=107) and the GOS had the least ICF categories.

The EuroQol was the second most cited measure. Both the EuroQol and the GOS are very concise measures consisting of only 5 items each. Their ICF representation in terms of bandwidth is very small, 2.8% and 2.5% respectively, but very specific in terms of which ICF categories they measure (content density = 2 and 1.8 respectively). Despite the limited number of items, the EuroQol represent eight ICF chapters (27%), two in the *body function* (b) component and six in the *activity and participation* (d) component.

The WHODAS II and the FIM were similar in their ICF representation with a respective bandwidth of 6.6% and 8.0%. Both measures covered nine chapters of the ICF with the WHODAS II containing eight categories in the *activity and participation* (d) component compared to five represented in the FIM.

The TOP was the only trauma specific measure, although cited only once (73). The TOP had the largest ICF representation with 61 categories (bandwidth=16.8%) and covered seventeen ICF chapters (57%). The TOP was the only measure to include items in the environmental factors component (n=4).

5.3.4 Overall representation of ICF categories contained in outcome measures

Only 18 (21%) of the 86 second level ICF categories identified occurred in more than three (50%) measures (Figure 5.3). Fourteen of thirty possible chapters were represented by items contained in the outcome measures. Two *body function* chapters *mental functions* (b1) and *sensory functions of pain* (b2) were frequently represented (>30%). No measure contained categories relating to chapter 8 *functions of the skin and related structures* (b8). All nine *activity and participation* chapters were represented and linked to forty five ICF categories, with 27% (n=32) second level categories frequently represented. Four *environmental factors* (e) were linked in one measure. Even administration of all outcome measures would result in poor assessment of the full breadth of the ICF.

Figure 5.3 Frequently represented (>30%) ICF chapters and categories linked in outcome measures

ICF

BODY FUNCTIONS (b) n=10	%
CHAPTER 1: Mental functions (b1)	
b117 Intelectual functions	33
b126 Tempramentand personality functions	33
b130 Energy and drive	33
b134 Sleep functions	33
b 140 Attention functions	33
b 144 Memory functions	50
b152 Emotional functions	67
b160 Thought functions	50
b180 Experience of self and time functions	33
CHAPTER 2: Sensory functions and pain (b2)	
b280 Sensation of pain	50

ACTIVITYAND PARTICIPATION (d) n=32	%
CHAPTER 1: Learning and applying knowledge (d1)	
d160 Focusing attention	33
d175 Solving problems	50
CHAPTER 2: General tasks and demands (d2)	
d230 Carrying out daily routine	33
d240 Handling stress	33
CHAPTER 3: Communication (d3)	
d310 Communication	33
d350 Conversation	33
CHAPTER 4: Mobility (d4)	
d410 Changing basic body position	50
d415 Maintaining a body position	33
d450 Walking	67
d455 Moving around	33
d465 Moving around using equipment	33
CHAPTER 5: Self-care (d5)	
d510 Washing oneself	83
d520 Caring for body parts	33
d530 Toiletting	33
d540 Dressing	83
d550 Eating	50
d560 Drinking	33
d570 Looking after one's health	33
CHAPTER 6: Domestic life (d6)	
d640 Doing housework	83
CHAPTER 7: Interpersonal interaction (d7)	
d710 Basic Interpersonal interaction	50
d720 Complex interpersonal interaction	33
d750 Informal social relationships	50
d760 Family relationships	67
d770 Intimate relationships	50
CHAPTER 8: Major life areas (d8)	
d820 School education	33
d825 Vocational training	33
d830 Higher education	33
d845 Acquiring, and keeping a job	33
d850 Remunerative employment	67
d870 Economic self-sufficiency	33
CHAPTER 9: Community, Social and civic life (d9)	
d910 Community life	50
d920 Recreation and leisure	67

ENVIRONMENTAL FUNCTIONS (e) n=3	%
CHAPTER 1: Products and technology (e1)	
e115 Products/technology for daily living	33
CHAPTER 3: Support and relationships (e3)	
e310 Immediate family	33
CHAPTER 4: Attitudes (e4)	
e410 Individual attitudes of family	33

Figure 5.3 Fourteen chapters and 45 second level ICF categories were frequently used in measures (relative frequency >30%). Of these, only 18 categories occurred in half of the measures.

5.4 Discussion

The review provides an overview of outcome measures frequently used in trauma studies. Additionally, it illustrates how many and which health outcomes are captured by these measures, using the ICF as a reference. It is evident by the small number of measures identified here, that the evaluation of health outcome remains inconsistent and absent despite decades of trauma research. The most comprehensive measure captures less than 5% of possible health outcomes, and there were significant gaps in domains of the environment and activity and participation. Existing outcome measures do not describe the impact of major trauma on function, disability and health. We therefore do not fully understand the health outcomes of trauma patients.

Measuring the population burden of major trauma is a complex task, made particularly difficult by the heterogeneity of patient populations and injury patterns (123). This task is made more problematic by the inconsistent use of outcome measures. Only five measures were used three times or more in studies included. Many of the outcome measures included in the analysis were generic. The SF-36 was cited most frequently and used in studies in the USA, Europe and the UK. This was not surprising as it is one of the most widely used generic measures to evaluate health related quality of life (445). While the consistent application of the SF-36 could allow international comparison of trauma outcome, it captures only a small proportion of health outcomes. The uptake is further limited by the licencing cost and length of time it takes to administer due to the number of questions (9). The measure with the greatest ICF representation (TOP) was cited only once (73) and requires further validation studies (459). Only one measure was developed within the ICF framework (WHODAS ll). Despite this the ICF representation is limited and important condition specific categories, such as the impact of scars and disfigurement are not captured. This large variation in measures, and the absence of functional tools in trauma registries (17) impedes comparison of outcome and an understanding of the impact of injury on different populations (169, 460).

Content analysis, confirmed that only a small proportion of health outcomes are captured by frequently used measures and there was little consistency across the measures in their coverage of the ICF. The absence of a comprehensive health outcome measure in major trauma limits focused clinical care and research (161, 461). Existing outcome measures do not fully describe the impact of major trauma on function, health and disability. There must therefore be some gaps in our understanding of outcome after trauma. The

importance of this can be illustrated by the important gaps identified in the existing tools – such as in areas related to environmental factors and participation. People may have the physical ability to do their own shopping but are unable to leave the house to go shopping due to stairs at the front door. Their participation is restricted by environmental factors. Environmental factors such as education, access to medical insurance, trauma systems and support services has all been shown to impact on outcome (462, 463). However, less than 2% of all environmental factors were captured with existing outcome measures used in trauma care. Similarly few measures truly capture return to work or the factors limiting return to work despite injury being the leading cause of death in working-aged adults (125). Health outcomes cannot be assessed without an understanding of participation restrictions and environmental barriers.

The use of generic outcomes measures is not unique to trauma. However there is generally a stronger consensus in terms of which measurement to use in conditions such as stroke, brain injury and in multiple sclerosis (172, 420, 464). In many ways, health outcome evaluation of these conditions is more advanced than in trauma studies. In recognition of the value of a standardised code based system for health outcome evaluation, ICF core sets exist for these and several other conditions (172, 464, 465). This framework enables local and population-wide evaluation. The lack of an ICF-based framework for trauma limits outcome evaluation and understanding of the true health impact of injury.

Limitations

The systematic review relied on a simplified review methodology, using specific rather than sensitive search strategies due to the heterogeneity of studies. Most included studies were observational in nature with only a few RCTs. However, the results reflect the current state of study design in trauma research. The majority of outcome measures included in the review and selected for mapping correspond with those recommended in previous trauma consensus papers (16, 160, 161, 350). I do not discuss the *body structures component* (s) of the ICF in any depth and only one measure, the TOP, included *body structures*. *Body structure* categories describe the body part or location of the 'problem' rather than the actual problem or health impact which was the purpose of the review. Moreover, *body structures* are captured by trauma scores such as the ISS and the Abbreviated Injury Scale (AIS) (466) which covers many aspects of *body structures.* These scores are used to determine mortality rather than morbidity and were thus not considered for inclusion in

the study. Finally, I only included English articles which excluded literature that may have pertained to a better understanding of the Hannover Score for Polytrauma Outcome.

Conclusion

Wide-ranging assessment tools are required to improve service provision, clinical research and ultimately patient outcomes (88, 272). Health outcomes after major trauma are not comprehensively described or captured due to limited outcome measures that assess only a small proportion of possible health impacts. The ICF represents a useful framework for future development of health outcomes instruments for trauma. While the framework can provide the necessary structure and standardised language, there is a need to take patients' perspective into consideration as well as the experience of health care professionals. The contribution of health care professionals' (HCPs) opinion is important to ensure the comprehensiveness of a possible measure as well as eventual application. Patient contribution will further aid in the inclusiveness and ensure patient centres outcomes are evaluated and considered. With this in mind I conducted the following two studies in chapter 6 and chapter 7.

Chapter 6: AN INTERNATIONAL SURVEY OF TRAUMA EXPERTS OPINION ON HEALTH PROBLEMS EXPERIENCED BY PEOPLE WITH MULTIPLE TRAUMATIC INJURIES

6.1 Introduction

The previous chapters discussed the importance and the need for comprehensive assessment of the requirements and abilities of trauma patients to enable improved patient outcomes and service and system effectiveness. Data from the previous studies in this thesis demonstrates that measures currently used in trauma do not capture the full extent of health outcomes that patients may experience. Moreover, despite much improvement in health care, rehabilitation complexity, access and intensity remains poorly recognised or measured in trauma.

Nurses, occupational therapists and physiotherapists use a variety of frameworks and models (288, 467, 468) to guide their practice and medical intervention is often coded with the ICD-10 (469). Although frameworks support communication and clarity amongst the same professionals, they are intended for uni-disciplinary use and may be a barrier to effective multi-disciplinary team working and communication. This in itself can limit effective goal setting, rehabilitation interventions or outcome assessment (470). Effective communication and shared information between team members concerning patient progress (471) and risk factors are essential to ensure optimal health outcome (472). The ICF is not profession specific and consequently provides a standardised language and structure to enable effective communication and patient management.

No previous studies investigate the use of the ICF in a trauma setting to facilitate communication or patient assessment. Moreover, it is unknown if HCPs working in trauma are familiar with the ICF as a framework or the ICF language. Previous studies engaged HCPs in Delphi surveys to identify ICF categories relevant to patients with traumatic brain injury (473) and spinal cord injury (474). However, this has not been undertaken in multiple traumatic injuries. The aim of this study was to explore trauma experts' opinion of important health outcomes after trauma. Specifically, I wanted to investigate this from a variety of professional backgrounds and use the ICF structure and language.

6.2 Methods

Chapter 2 section 2.6.2 has additional information on the methods used for this study.

6.2.1 Study Design

A quantitative international expert survey was conducted using an on-line questionnaire to ensure time and cost-effective data collection.

6.2.2 Inclusion and exclusion criteria

Any HCP registered with a professional body with at least five years' experience of working in trauma and able to read and write English were able to participate. Health care professionals included doctors, nurses, physiotherapists, occupational therapists, psychologists, social workers, dieticians and speech and language therapists (not an exhaustive list). I was unable to accommodate HCPs that did not have access to the internet due to cost implications and time frames.

6.2.3 Instrument

The Comprehensive Acute and Post-Acute ICF Core Sets (269, 361-363) were used as the basis for the on-line questionnaire. These ICF Core Sets, consisting of 140 ICF categories, were developed by experts working in orthopaedic, neurological and cardio-vascular conditions using a Delphi process and patient focus groups. I chose to use these Core Sets as trauma patients have similar health needs as patients in these three groups in the early phases post-trauma (361, 475, 476). The 140 categories of the core sets consisted of 57 *body function categories*, 13 *body structure* categories, 40 *activities and participation* categories and 30 *environmental factors*. A questionnaire was constructed based on these categories and delivered via an online web platform, Survey Monkey® (366).

A Delphi study was not regarded necessary as the Core Sets had already gone through a rigorous process. Rather, HCPs were asked to rate the prevalence (how common a category is) and the impact this can have on health outcome (the importance) should the problem occur. This data will be used to determine the overall relevance and importance of ICF categories. Some problems may not be very common but can have a significant impact on outcome and should be given greater importance. The questionnaire was divided into two parts (Appendix 6). Part one collected personal non identifiable data

required for the description of the study population. Part two presented the 140 ICF categories.

6.2.4 Recruitment and data collection

Two groups of trauma experts were approached to participate in the questionnaire. Group one was purposively selected (367) known experts in trauma care. The second group of HCPs were recruited through web based invitations posted on profession specific bodies or special interest group websites. For example: members from the World Federation for Occupational Therapy and the International Society for Physical and Rehabilitation Medicine responded to an on-line invitation for participation Consent to participate was obtained at the start of the on-line questionnaire.

6.2.5 Data analysis

Descriptive statistics was used to analyse the frequency of categories identified by health care professionals. Open ended and free text answers were analysed using established linking rules described in Chapter 2 (370, 371). Each ICF category contained two responses. One specified how common a category was (not common, common or very common) and the other the importance (not important, important, very important). The average was calculated for responses that indicated a category was 'common or very common' and 'important or very important'. The average is presented as a percentage, representing how many HCPs regarded a specific ICF category as common (prevalent) or important. ICF categories with an average prevalence and importance of 50% or more were included and considered important in trauma care.

6.3 Results

Three hundred and twenty nine HCPs consented to participate and 217 completed the questionnaire (65%) (Table6.1). From the 210 invited trauma experts in group one, 179 agreed to participate and 128 (72%) completed the questionnaire. Group two, who were HCPs that participated in response to invitations on specialist membership websites, had 150 participants with a completion rate of 57% (n=86).

Table 6.1 Demographics of health care professionals who commenced the online questionnaire

	n	%
Total questionnaire commenced	329	100%
Male	131	40%
Allied Health Professionals (AHPs) including trauma managers	224	68%
Medical Practitioners	105	32%
5 to 8 years' experience	73	22%
More than 8 years' experience	256	78%
Acute setting	216‡	66%
Major Trauma Centre (Specialist acute hospital)	137	63%
Trauma Unit (General acute hospital)	61	28%
Hospital (Undefined)	18	8%
Post-acute Setting	173‡	53%
Generic in-patient rehabilitation	30	17%
Specialist in patient rehabilitation	63	36%
Skilled Nursing Facility	9	5%
Forensic unit	2	1%
Community rehabilitation team	38	22%
Out patients	26	15%
Other	5	3%

‡ 61 HCPs worked in both acute and post-acute settings

The majority of HCPs that commenced the questionnaire had more than 8 years' experience of working with people with traumatic injuries (n=256; 78%), and mainly worked in acute care setting (n=216; 66%) (Table 6.1) Nineteen percent (n=61) of participants worked in both the acute and post-acute setting. 68% (n=224) of the respondents were allied health professionals which included therapist, nurses and trauma managers. 32% (n=105) were doctors from a variety of professional backgrounds including emergency department, general surgeons, traumatologists, intensivists, anaesthetists, vascular- and orthopaedic surgeons and rehabilitation physicians. There was an absence of participation from psychiatrist, GP's and pharmacists. 86% (n=121) of the 140 ICF categories presented to the HCPs were regarded as relevant for trauma patients (≥50 % common and important) (Table 6.2 – Table 6.5).

Forty three from a possible 51 *body function* categories were rated as important by HCPs. Twelve *body function* (b) categories had a prevalence and importance greater than 80% of which pain, muscle power and problems with joint mobility were the most frequently identified by HCPs (Table 6.2). The most categories with the highest frequencies related to chapter 1 (*mental functions*) and chapter 7 (*neuro musculoskeletal and movement-related functions*). Two categories each, all with low importance, were identified for body functions of *voice and speech functions* (chapter 4), *genitourinary and reproductive functions* (chapter 6) and *functions of the skin and related structures* (chapter 8).

Table 6.2 Body Function categories (n=43) identified by 50% of health care professionals

Body Functions	Very Common	Very Important	Average ≥ 50%
CHAPTER 1: Mental functions			
b110 Problems with level of consciousness	71%	87%	79%
b114 Problems with orientation (time, place person)	83%	86%	84%
b126 Problems with temperament and personality	78%	87%	83%
b130 Reduced energy and drive functions (fatigue)	87%	87%	87%
b134 Problems with sleep (too much/too little)	83%	83%	83%
b140 Problems with attention	83%	84%	84%
b144 Memory problems (short or long term memory)	85%	90%	88%
b147 Psychomotor problems (coordination)	75%	83%	79%
b152 Emotional problems	86%	86%	86%
b156 Perceptual problems	63%	76%	69%
b160 Problems with thoughts or ideas	71%	75%	73%
b164 Higher-level cognitive problems (executive functions.)	77%	86%	81%
b167 Problems with recognising & using signs in language	47%	67%	57%
b176 Problems sequencing complex, purposeful movements	60%	74%	67%
b180 Problems with self-awareness and awareness of time	69%	75%	72%
CHAPTER 2: Sensory functions and pain			
b210 Problems with seeing/vision	47%	74%	60%
b235 Problems with vestibular control	44%	71%	58%
b260 Problems with proprioception	50%	73%	62%
b265 Problems with touch sensation (tactile/texture)	47%	65%	56%
b280 Problems with pain	93%	96%	95%
CHAPTER 3: Voice and speech functions			
b320 Problems with articulation (production of speech)	51%	69%	60%
CHAPTER 4: Functions of the cardiovascular, haematological, immunological and respiratory systems			
b420 Problems with blood pressure	69%	75%	72%
b430 Problems with haematological system	52%	64%	58%
b440 Problems with respiration functions	67%	78%	72%
b445 Problems with respiratory muscle functions	51%	72%	61%
b455 Problems with exercise tolerance	84%	80%	82%
b460 Sensation of cardiac and respiratory problems (shortness of breath)	45%	59%	52%

Body Functions	Very Common	Very Important	Average ≥ 50%
CHAPTER 5: Functions of the digestive, metabolic and endocrine systems			
b510 Problems with Ingestion (eating and drinking)	63%	72%	68%
b525 Problems with defecation	61%	67%	64%
b530 Problems with weight maintenance	66%	67%	67%
b545 Problems with water, mineral and electrolyte balance	51%	62%	56%
CHAPTER 6: Genitourinary and reproductive functions			
b610 Problems with urinary excretory functions	48%	59%	54%
b620 Problems with urination	60%	68%	64%
CHAPTER 7: Neuro musculoskeletal and movement-related functions			
b710 Problems with joint mobility (range/ease of movement)	88%	92%	90%
b715 Problems with joint stability	77%	84%	80%
b730 Problems with muscle power	91%	92%	92%
b735 Problems with muscle tone	74%	82%	78%
b740 Problems with muscle endurance	82%	78%	80%
b755 Problems with involuntary movement reactions	43%	60%	51%
b760 Problems with control of voluntary movement	67%	78%	72%
b770 Problems with gait pattern (walking, running)	82%	85%	83%
b780 Problems with sensations related to muscles and movement functions	61%	70%	66%
CHAPTER 8: Functions of the skin and related structures			
b820 Repair functions of the skin (wound healing)	64%	75%	69%

From the 12 *body structures* (s) included, structures of the brain (s110) had the greatest importance (Table 6.3). Several body structures were rated as not commonly affected in trauma (meninges s130, cardiovascular system s410 and) although the impact could be significant if they were affected (Table 6.3). Structure of the stomach s530 was the only *body structure* presented in the questionnaire which had a prevalence and importance less than 50%. Four out of eight chapters had no categories identified with chapter 7, *structures related to movement* containing the most categories.

Table 6.3 Body Structure (n=12) categories identified by 50% of health care professionals

Body Structures	Very Common	Very Important	Average ≥ 50%
CHAPTER 1: Structures of the nervous system			
s110 Structures of brain	84%	94%	89%
s120 Spinal cord and related structures	67%	92%	80%
s130 Structures of meninges	40%	73%	56%
CHAPTER 2: The eye, ear and related structures			
CHAPTER 3: Structures involved in voice and speech			
CHAPTER 4: Structures of the cardiovascular, immunological and respiratory systems			
s410 Structures of cardiovascular system	53%	77%	65%
s430 Structures of respiratory system	69%	79%	74%
CHAPTER 5: Structures related to the digestive, metabolic and endocrine systems			
CHAPTER 6: Structures related to genitourinary and reproductive systems			
CHAPTER 7: Structures related to movement			
s710 Structures of head and neck region	74%	85%	79%
s720 Structures of shoulder region	72%	82%	77%
s730 Structures of upper extremity	84%	87%	85%
s740 Structures of pelvic region	70%	88%	79%
s750 Structures of lower extremity	84%	91%	88%
s760 Structures of trunk	74%	85%	79%
CHAPTER 8: Skin and related structures			
s810 Structures of areas of skin	68%	73%	70%

Thirty eight from a possible 40 *activity and participation* (d) categories were included (Table 6.4). Twenty of these categories (53%) were regarded as significant by 80% of HCPs. HCPs rated *problems with walking* (d450) as the most prevalent and important problem experienced by patients after trauma. *Moving around in different locations* (d460), *family relationships* (d760), *drying oneself* (d510) and *dressing* (d540) were all rated as very important and prevalent. All nine categories of *mobility* (chapter 4) and all seven categories in *self-care* (chapter 5) received very high ratings (≥79%) from HCP. There were no categories identified in chapter 6 (*domestic life*). Chapter 7 (*interpersonal interactions and relationships*) and chapter 8 (*major life areas*) had one category each which were *family relationships* (d760) and *economic self-sufficiency* (d870). HCPs did not regard items related to *community, social and civic life* (chapter 9) as very important although three categories were included in the questionnaire.

Table 6.4 Activity and Participation categories (n=38) identified by 50% health care professionals

Activity and Participation	Very Common	Very Important	Average ≥ 50%
CHAPTER 1: Learning and applying knowledge			
d110 Problems with watching	44%	64%	54%
d115 Problems with listening	55%	73%	64%
d135 Problems with rehearsing	48%	61%	54%
d155 Problems with acquiring skills	66%	80%	73%
d160 Problems with focusing attention	79%	87%	83%
d166 Problems with reading	58%	70%	64%
d170 Problems with writing	61%	73%	67%
d175 Problems with problem solving	74%	85%	79%
d177 Problems with making decisions	77%	86%	81%
CHAPTER 2: General tasks and demands			
d230 Problems with carrying out daily routine	84%	88%	86%
d240 Problems with handling stress	82%	89%	85%
CHAPTER 3: Communication			
d310 Problems with communicating with	63%	79%	71%
d315 Problems with communicating with –	64%	75%	69%
d330 Problems with speaking	54%	74%	64%
d335 Problems with producing nonverbal messages	40%	64%	52%
d350 Problems with conversation	59%	70%	65%
d360 Problems with using communication devices and techniques	48%	66%	57%
CHAPTER 4: Mobility			
d410 Problems with changing basic body position	78%	87%	83%
d415 Problems with maintaining a body position	73%	85%	79%
d420 Problems with transferring oneself	80%	89%	84%
d430 Problems with lifting and carrying objects	84%	85%	84%
d440 Problems with fine hand use	77%	88%	83%
d445 Problems with hand and arm use	69%	87%	78%
d450 Problems with walking	88%	93%	91%
d460 Problems with moving around in different locations	84%	88%	86%
d465 Problems with moving around using equipment	77%	87%	82%
CHAPTER 5: Self-care			
d510 Problems with washing and drying oneself	84%	88%	86%
d520 Problems with caring for body parts	80%	84%	82%
d530 Problems with toileting	78%	92%	85%
d540 Problems with dressing	83%	89%	86%
d550 Problems with eating	72%	90%	81%
d560 Problems with drinking	70%	88%	79%
d570 Problems with looking after one`s health	80%	85%	82%

Activity and Participation	Very Common	Very Important	Average ≥ 50%
CHAPTER 6: Domestic life			
CHAPTER 7: Interpersonal interactions and relationships			
d760 Problems with family relationships	83%	91%	87%
CHAPTER 8: Major life areas			
d870 Problems with economic self-sufficiency	82%	84%	83%
CHAPTER 9: Community, social and civic life			
d910 Problems with engaging in community life	81%	83%	82%
d930 Problems with engaging in religion and spirituality	44%	58%	51%
d940 Human rights	47%	64%	55%

In terms of the component *environmental factors* (e) twenty six from a possible 28 categories were regarded as relevant by HCPs (Table 6.5). HCPs identified environmental barriers and facilitators to recovery and also rated how common these categories are and the importance of them. The most important facilitators to recovery were *support and relationships* (chapter 3) of family (e310), friends (e320) and health professionals (e355). Overall, products and technology for personal use in daily living (e115) was identified as an important facilitator to recovery and includes equipment for personal use such as wheelchairs, walking aids or self-care equipment such as bath boards or bath seats. Services, systems and policies (chapter 5) were also perceived as helpful during recovery with a high prevalence and importance.

Surprisingly, *sound* (e250) e.g. banging, ringing or buzzing was considered as the biggest environmental barrier (86%) although the prevalence of this occurring was lower (65%). This category could be relevant in an acute care setting where medical devices are equipped with alarms. Access to private and public buildings (e150 and e155) was the second most identified barrier to recovery. Social norms (e465) and the legal system (e550) were selected by 52% of HCPs. Although HCPs rated many of the 26 categories with a high prevalence (on average 75%) and importance (85%) they did not rate their impact on recovery in terms of barriers (average of 33%) and facilitators (average of 67%) very high.

Table 6.5 Environmental barriers and facilitators (n=26) identified by 50% health care professionals

Environmental Barriers and Facilitators	Barriers	Facilitators	Very Common	Very Important	Average ≥ 50%
CHAPTER 1: Products and technology					
e110 Products for personal consumption and ingestion (food, drink and drugs)	32%	68%	65%	75%	70%
e115 Products and technology for personal use in daily living (walking stick, bath board)	11%	89%	71%	83%	77%
e120 Products and technology for personal indoor and outdoor mobility and transportation	22%	78%	71%	87%	79%
e125 Products and technology for communication (computers, mobile phones)	26%	74%	66%	78%	72%
e150 Design, construction and technology of building for public use	57%	43%	67%	82%	75%
e155 Design, construction and technology of building for private use	63%	38%	67%	85%	76%
CHAPTER 2: Natural environment and human-made changes to the environment					
e250 Sound (e.g. banging, ringing, buzzing, in any volume that is useful/distracting)	87%	13%	61%	68%	65%
Chapter 3 Support and relationships					
e310 Immediate family (by birth or marriage)	22%	78%	92%	94%	93%
e315 Extended family (uncles, aunts, nieces)	21%	79%	77%	82%	80%
e320 Friends	18%	82%	87%	90%	88%
e340 Service providers that enable work, education etc (nanny, cleaners)	16%	84%	65%	81%	73%
e355 Health professionals (doctors, nurses, therapists)	11%	89%	90%	96%	93%
e360 Health related professionals (lawyers, social workers, teachers, architects)	16%	84%	76%	84%	80%

Environmental Barriers and Facilitators	Barriers	Facilitators	Very Common	Very Important	Average ≥ 50%
Chapter 4 Attitudes					
e410 Attitudes of immediate family members that influence individual behaviour	39%	61%	92%	97%	94%
e415 Attitudes of extended family members that influence behaviour or actions	40%	60%	78%	86%	82%
e420 Attitudes of friends (specific opinions that that influence behaviour or actions)	34%	66%	81%	88%	85%
e430 Attitudes of people in positions of authority that influence behaviour or actions	46%	54%	72%	84%	78%
e440 Attitudes of personal care providers and personal assistants	29%	71%	75%	86%	81%
e450 Attitudes of health professionals	25%	75%	83%	92%	87%
e455 Attitudes of other professionals	31%	69%	72%	82%	77%
e465 Social norms, practices and ideologies (moral and religious behaviour or etiquette)	53%	47%	72%	82%	77%
Chapter 5 Services, systems and policies					
e550 Legal services, systems and policies (legislation and other law of a country)	52%	48%	73%	86%	80%
e555 Associations, memberships and organizational services (e.g. charities)	14%	86%	51%	69%	60%
e570 Social security, services, systems & policies (income support, unemployment)	45%	55%	85%	95%	90%
e575 General social support services (help with shopping, housework, self-care and care)	29%	71%	79%	92%	85%
e580 Health services, systems and policies (rehabilitation & promotion healthy lifestyle)	27%	73%	85%	93%	89%

Table 6.6 Personal factors identified by health care professionals

Factors facilitating coping	%	n =414	Factors preventing coping	%	n =328
Attitude to life	40%	86	Attitude to life	30%	66
Family upbringing	34%	74	Social Background / life style	29%	64
Social background	24%	53	Education	16%	34
Education	22%	48	Social support	14%	31
Social support	21%	45	Age	12%	27
Employment	13%	29	Family upbringing/ support	12%	27
Access to Services	12%	26	Employment	10%	21
Age	10%	21	Substance abuse	6%	14
Psychology access	5%	10	Services	6%	14
Access to finance	3%	7	gender	3%	7
Faith	3%	6	Race	3%	7
Injury severity	1%	3	Cost of care	3%	6
gender	1%	2	Injury severity	2%	4
Litigation	1%	2	Co morbidities	1%	3
Race	0%	1	Cognitive impairment	1%	2
Other	0%	1	Litigation	0%	1

Table 6.6 HCPs identified 742 personal factors which could either help or hinder recovery such as age, education and attitude.

6.4 Discussion

This study demonstrates that it is possible to use a recognised framework to identify health outcomes related to trauma patients as perceived by expert HCPs working in trauma. The high level of agreement between a large international cohort of HCPs confirms that the data may be relevant to international trauma populations. Moreover, agreement between a vast mix of HCPs including doctors and allied health professionals confirms that it is possible to apply the ICF as a standard language in trauma care.

By dividing health concepts into prevalence and significance groups I was able to gain a greater understanding of HCPs concerns related to outcome. This method allowed me to identify overall important categories as well as less common problems which could have a considerable impact on outcome. Only 15% of the 140 categories were regarded as less important. This high level of agreement demonstrates the legitimacy and applicability of the Acute and Post-Acute ICF Core Set (396).

The *body functions* categories with the highest frequency related to *mental functions* (chapter 1) and *neuro musculoskeletal and movement-related functions* (chapter 7). *Mental function* categories included *emotional functioning* (b152), *energy and drive functions* (b130), *temperament and personality functions* (b126) and *problems with orientation* (b114). Emotional functioning has been evaluated in several previous studies (54, 437, 477) although this mostly focused on post-traumatic stress (478-480), acute stress (480-483) or quality of life (346, 484, 485). Aspects related to other mental functions such as *higher-level cognitive problems* (b164), *attention* (b140) and *memory problems* (b144) are not routinely assessed as part of trauma outcomes. Traumatic brain injury research emphasises the importance of considering the impact of even mild brain injury due to the impact this can have on personality, daily life, sleep and fatigue (*energy and drive functions*) and executive functions (486-490). Despite this, cognition and fatigue are not routinely assessed in trauma outcomes (127, 491, 492) despite 80% of clinicians regarding these categories as important.

The questionnaire presented only 12 *body structures* to the HCPs. Many medical practitioners rely on the ISS to classify severity of injury related to body structures and they may not necessarily regard body structures as an important consideration in rehabilitation. Surprisingly, *structures of the stomach* (s530) were viewed as un-important despite the frequent occurrence and necessity of laparotomies in unstable patients in acute trauma care (493-496). The frequency of categories in *structures related to movement* (chapter 7) is in accordance with trauma literature where research may focus on lower limb orthopaedic injuries (31, 497-499), amputations (30, 500) or upper limb impairments (501, 502). This also correlates with categories identified in the *activity and participation* component where 9 categories in the *mobility* chapter (chapter 4) were regarded as significant (>80%).

Domestic tasks (chapter 6) such as shopping, cooking and cleaning, were not considered as relevant and to my knowledge have not been investigated in trauma. HCPs prioritised categories of *mobility* (chapter 4) *and self-care* (chapter 5). Although several trauma studies report functional outcome, they frequently use generic QOL measures such as the EuroQol or the SF-36 (63, 435). These measures are designed to evaluate health rather than function, although function is part of health (503) which implies limited actual evaluation of function or activities after trauma. Moreover, the systematic review in chapter 5 demonstrated that very few ICF self-care categories are captured by these

measures (163) (Appendix 9). The FIM is used in a limited number of trauma studies (390, 504), although more recent studies found that it is inappropriate for use in trauma outcome studies (176, 505, 506). The data suggests that HCPs recognise the impact trauma has on function and that more needs to be done to measure actual activity limitations as the measures in current use are not fit for purpose (176).

The family was another area of high importance in the *activity and participation* component *(family relationships*, d760) and the *environment component* (*support and relationships of family*, e310), although this receives very little attention in the trauma literature (507, 508).

Environmental factors are not routinely considered or evaluated in trauma outcomes and previous ICF studies in other conditions confirmed the lack of consideration of this component (509, 510). Categories such as *access to private and public buildings* (e150 and e155) were regarded as barriers, and *products and technology for personal use in daily living* (e115) was regarded as a facilitator by a large proportion of HCPs. However, these are not routinely measures or the impact considered which can significantly affect recovery and participation in meaningful activities. The importance of environmental factors on recovery has recently been demonstrated in other conditions (511) and requires further consideration in trauma care.

Limitations

This study has some limitations. The average percentage was calculated for the common and very common problems and important and very important categories. This approach to analysis may have caused inclusion of categories which were of less concern. For example, 50% of HCPs rated proprioception (b260) as an uncommon problem; 40% rated it as common and 10% as very common, thus a combined total of very common of 50%. However, the intention was not to reduce the amount of categories but to rather ensure all relevant categories are included.

The response options in the questionnaire were nominal categories of prevalence and importance of injuries. These nominal categories could have been presented as numerical categories or a Likert scale which would have allowed additional data analysis of complexity or ranking of categories to determine consensus (512-514). Nevertheless, as these

categories were already identified through a rigorous Delphi process I did not consider this necessary.

Remunerative employment (d850) does not occur in the Comprehensive ICF Core Set and was not included in the HCP questionnaire. This is an important limitation as trauma patients are young and or working age and employment and return to employment should be considered.

Conclusion

A large group of international trauma experts was able to understand and select ICF categories relevant to trauma patients. This confirmed that the ICF language may be clear and acceptable to HCPs working in trauma. Experienced HCPs identified a variety of health outcomes which are not currently captured within existing outcome measures. Therefore health outcome is not comprehensively measured in trauma systems or trauma research. Consequently, our understanding of the impact of these components is limited as they are not routinely evaluated. In an effort to explore these health outcomes and impacts further and to gain a holistic understanding of outcomes after trauma I conducted a qualitative study to gain patients perceptions of outcome.

Chapter 7: PATIENT PERSPECTIVE OF HEALTH OUTCOME FOLLOWING MAJOR TRAUMA

7.1 Introduction

Although a wide variety of outcome measures are used to assess morbidity after trauma (347, 502), many of them fail to evaluate the patients' perception of health outcome and recovery (20, 197, 515). The objective assessment with generic outcome measures does not capture the subjective experience of trauma survivors (50, 60, 516) and there is an absence of qualitative trauma studies (471). As a consequence, little is known about the specific effects that traumatic injury has on health outcomes important to patients such as participation in life events or barriers and facilitators to recovery (517, 518).

Qualitative research is one way of obtaining robust subjective, non-numerical data about a phenomenon and has been recommended for use in trauma outcome research (519). It is an essential component for the development of patient-reported outcome measures (PROM's) (520) and used in the early stages of development of outcome measures (521). However, there are currently no trauma specific outcome measure or trauma PROM's based on qualitative patient studies. Moreover, data on patient perspective will allow the development of a person centred trauma service ensuring patient centred goals, care co-ordination, information and support (522).

The systematic review (Chapter 5) discussed outcome measures used in trauma studies but also highlight the lack of patient centred measures specifically developed with and for trauma survivors. The previous chapter investigated health categories which are considered relevant by expert HPCs. The objective of this study was to expand on the work of the previous studies to gain a patient perspective of important health outcomes after trauma, using the ICF as a reference.

7.2 Methods

More detail on methods and justification of methods can be found in section 2.7 of this thesis.

7.2.1 Study Design

Qualitative semi-structured face to face patient interviews were conducted with individuals who experienced traumatic injuries. The purpose of the patient interviews was to gain an understanding of health issues experienced after sustaining a traumatic injury. The ICF was used as a framework for analysis.

7.2.2 Population

Participants were recruited from the RLH major trauma centre in London. Discharged adult patients and a small cohort of in-patients were approached to participate in the study.

7.2.3 Inclusion and exclusion criteria

Patients aged eighteen years or older who sustained a traumatic injury and able to consent were included. Individuals who did not have capacity to participate or consent, e.g. severe brain injury were excluded.

7.2.4 Sampling

Maximum variation sampling (376) was used for this study. I used this sampling to identify patients based on two criteria: injury severity (<16 and ≥16) and age (≤34 and ≥35 years old). Time since injury was also considered whilst selecting the two groups of patients. This form of purposive sampling (381) was used to obtain a wide-ranging representation of the heterogeneous patient population (304). These criteria were used to manage recruitment of patients. A sample size of 30 patients was chosen as discussed in section 2.7.5.

7.2.5 Recruitment

After application of the sampling and inclusion criteria, the appropriate patients were informed about the study during a routine follow up call from the TOU and invited to participate. Interviews were scheduled to coincide with other hospital appointments where possible to reduce patient burden.

7.2.6 Instruments

An interview guide containing 6 questions based on the components *Body Structures, Body Functions, Activities and Participation, Environmental Factors* and *Personal Factors* of the ICF was used to structure questions. Additional open-ended questions were used to prompt patients if they had difficulty understanding the question. An example of the topic guide can be found in (Appendix 7).

7.2.7 Data collection

All interviews were conducted by the primary researcher (KH). Written consent was obtained at the time of the face-to-face interview. All interviews were digitally recorded and brief notes were taken during the interview where possible. Recordings were transcribed verbatim.

7.2.8 Data analysis

Transcribed interviews were analysed using the meaning condensation procedure (393, 394), described in more detail in Chapter 2, Section 2.7.6. The process of meaning condensation is very similar to the process of ICF linking, discussed in Section 2.5.1. Transcribed interview data were grouped into meaning units and then linked to ICF categories according to published linking rules (350, 371). Items that were linked to the third- and fourth-level categories were aggregated to second level categories.

Absolute and relative frequencies were calculated for ICF categories identified in patient interviews. Frequency analysis is discussed in detail in Section 2.5.2. The absolute frequency was used to capture the *magnitude* of the concepts where the relative frequency was used to establish the *prevalence* of concepts or categories. Once ICF categories were identified, a descriptive summary of the results was sent to patients and returned to ensure all important aspects were captured in the interviews. This process of member checking, sometimes referred to a respondent validation (304), was completed in an effort to validate data accuracy (397). Categories reported by more than 5% of patients were considered for inclusion in the final analysis and manuscript.

7.3 Results

Forty four participants were invited to participate and 35 participants (80%) consented and were interviewed. Three interviews were excluded due to content referring to ongoing medical issues not related to their trauma. A diverse sample was achieved using maximum variation strategy. Interviews included two inpatients and the remainder were those who had been discharged to the community. Overall the majority of participants (84%) were male with an average age of 37 years (range 18-75). Participants with blunt injuries were older (42 years vs. 25 years old) and had longer timeframes since injury (9 months vs. 4 months) but similar Injury Severity Scores (ISS: 20 vs. ISS: 22) compared to participants with penetrating injuries (Table 7.1).

Participants who did not provide written consent (n=9) were all younger males (30 years), more recently injured (3-9 month post injury) with more severe injuries (ISS: 25). Of these, six did not attend their out-patient clinic appointment after providing telephone verbal consent, two opted not to participate as they were too busy and one patient could not be reached after he was included in the sample. Only nine patients responded to the member checking (respondent validation) document (28%) but all agreed that the content of the document was an accurate summary of their experience and interview.

Table 7.1 Demographic information for patients invited to participate in interviews

	All	**Blunt**	**Penetrating**	**≤34yrs**	**≥35yrs**	**Not consented**
Total n (%)	32	28(88%)	4(13%)	15(47%)	17(53%)	9(20%)
Age (range)	37(19-75)	42(19-75)	25(21-29)	27(19-31)	53(37-75)	30(18-53)
Male (%)	27(84%)	22(69%)	4(16%)	15(47%)	12(38%)	9(100%)
ISS (range)	20(4-45)	20 (4-45)	22(16-30)	20(4-43)	20(4-43)	25(9-43)
Length of stay (range of days)	14(2-86)	14 (3-82)	23 (2-62)	14(3-86)	14(4-34)	14(6-79)
Time since injury (range of months)	5(1-36)	9(0-36)	4(3-12)	5(1-36)	6(0-28)	3(3-9)

Table 7.1 Presents median data for age, ISS, length of stay and time since injury

A total of 2742 health concepts were extracted from the interviews. These were linked to 388 second and third level ICF categories. All third level categories (n=223) were grouped into second level categories resulting in a total of 234 second level ICF categories. 146 of the 234 categories (62%) were identified by two or more patients and had a relative frequency of greater than 5% (Table 7.2 to Table 7.5). Fifty five concepts were to general to be linked or related to personal factors which currently do not have ICF categories. An average of 86 ICF categories was identified per patient (range: 15 to 182 categories).

All eight chapters in the *body function component* (b) were represented (Table 7.2). Categories related to *mental functions* (chapter 1), *sensory functions and pain* (chapter 2) and *repair function of the skin* (chapter 8) were linked the most frequently. Problems with temperament and personality (b126), reduced energy functions (b130) and emotional problems (b152) were mentioned by at least 80% of the patients.

Table 7.2 Body function categories identified by >5% of patients (n=49)

Body Functions	Relative frequency	Absolute frequency
CHAPTER 1: Mental functions		
b110 Problems with level of consciousness	9%	25%
b114 Problems with orientation (time, place person etc)	16%	25%
b126 Problems with temperament and personality functions	88%	431%
b130 Reduced energy and drive functions (fatigue, disinterest)	81%	228%
b134 Problems with sleep (too much/too little/altered pattern)	47%	131%
b140 Problems with attention	34%	59%
b144 Memory problems (short or long term memory)	56%	163%
b147 Psychomotor problems	9%	13%
b152 Emotional problems	81%	372%
b156 Perceptual problems	9%	19%
b160 Problems with thoughts or ideas	34%	72%
b164 Higher-level cognitive problems (executive functions)	28%	100%
b167 Problems with recognising & using signs/symbols	13%	38%
b180 Problems with self-awareness and awareness of time	56%	172%
CHAPTER 2: Sensory functions and pain		
b210 Problems with seeing/vision	13%	38%
b230 Problems with hearing problems	6%	13%
b235 Problems with vestibular control	13%	28%
b260 Problems with proprioception	3%	3%
b265 Problems with touch sensation (tactile/texture)	16%	22%
b270 Problems with sensation of temperature and other stimuli	13%	13%
b279 Additional sensory functions, other specified	6%	6%
b280 Problems with pain	81%	275%
b298 Sensory functions and pain, other specified	9%	9%
CHAPTER 3: Voice and speech functions		
b310 Problems with voice (quality of voice and sound)	6%	6%
b320 Problems with articulation (production of speech sounds)	6%	6%
b330 Fluency and rhythm of speech functions	6%	9%
CHAPTER 4: Functions of the cardiovascular, haematological, immunological and respiratory systems		
b430 Problems with haematological system	13%	19%
b435 Problems with immune system	16%	34%
b440 Problems with respiration functions	13%	22%
b450 Problems with additional respiratory functions (coughing)	9%	13%
b455 Problems with exercise tolerance	41%	91%
b460 Cardiac and respiratory problems (shortness of breath)	6%	6%

Body Functions	Relative frequency	Absolute frequency
CHAPTER 5: Functions of the digestive, metabolic and endocrine systems		
b510 Problems with Ingestion (eating and drinking)	9%	25%
b515 Problems with digestion	6%	6%
b525 Problems with defecation	13%	13%
b530 Problems with weight maintenance	25%	28%
b535 Problems with the digestive system (bloated/indigestion)	6%	6%
b550 Thermoregulatory functions	6%	13%
CHAPTER 6: Genitourinary and reproductive functions		
b620 Problems with urination	16%	19%
CHAPTER 7: Neuro musculoskeletal and movement-related functions		
b710 Problems with joint mobility (range/ease of movement)	13%	38%
b720 Mobility of bone functions	6%	13%
b730 Problems with muscle power	28%	38%
b735 Problems with muscle tone	19%	22%
b740 Problems with muscle endurance	13%	13%
b760 Problems with control of voluntary movement	9%	13%
b770 Problems with gait pattern (walking, running)	9%	19%
b780 Problems with sensations muscles and movement	6%	9%
CHAPTER 8: Functions of the skin and related structures		
b810 Protective functions of the skin (temperature control)	9%	9%
b820 Repair functions of the skin (wound healing)	56%	138%
b840 Sensation related to the skin	13%	13%

In terms of *body structures* (s) (Table 7.3) there was a very small representation of categories (n=19). Chapter 7, *Structures related to movement* had three times more categories than the other chapters and *structures of lower extremity* (s750) were mentioned the most frequently (63%). Less than half of the patients (31%) reported impairments to the head and neck region (s710) although this correlated with the number of patients with head injuries. Impairments in the upper limb (s730) and the trunk (s760), although in the top four, were reported by less than 30% of patients.

Table 7.3 Body structure categories identified by >5% of patients (n=19)

Body Structures	Relative frequency	Absolute frequency
CHAPTER 1: Structures of the nervous system		
s110 Structures of brain	19%	50%
s120 Spinal cord and related structures	9%	13%
CHAPTER 2: The eye, ear and related structures		
s220 Structure of eyeball	6%	13%
s230 Structures around eye	6%	16%
CHAPTER 3: Structures involved in voice and speech		
s320 Structure of the mouth	9%	16%
CHAPTER 4: Structures of the cardiovascular, immunological and respiratory systems		
s420 Structure of immune system	6%	6%
s430 Structures of respiratory system	22%	59%
CHAPTER 5: Structures related to the digestive, metabolic and endocrine systems		
s530 Structures of stomach	16%	25%
s560 Structure of liver	6%	9%
CHAPTER 6: Structures related to genitourinary and reproductive systems		
s610 Structure of urinary system	9%	16%
CHAPTER 7: Structures related to movement		
s710 Structures of head and neck region	31%	66%
s720 Structures of shoulder region	13%	25%
s730 Structures of upper extremity	28%	50%
s740 Structures of pelvic region	16%	28%
s750 Structures of lower extremity	63%	159%
s760 Structures of trunk	25%	34%
s770 Additional musculoskeletal structures related to movement	6%	16%
CHAPTER 8: Skin and related structures		
s810 Structures of areas of skin	6%	9%
s820 Structure of skin glands	6%	6%

The *Activity and Participation component* (d) (Table 7.4) contained the most frequently reported categories with 17 categories reported by more than a third of patients of patients. The most important categories were remunerative employment (d850) (84%), recreation and leisure (d920) (75%), looking after one's health (d570) (72%) and walking (d450) (69%). Stress and other psychological demands (d240) was mentioned by less than half of the patients (44%) but had a very high absolute frequency (200%) indicating the impact this had on individuals lives. The majority of the problems were identified in chapter 4, which relates to *mobility* issues (n=12 categories).

Table 7.4 Activity and participation categories identified by >5% of patients (n=50)

Activity and Participation	Relative frequency	Absolute frequency
CHAPTER 1: Learning and applying knowledge		
d160 Problems with focusing attention	9%	9%
d163 Thinking	9%	9%
d166 Problems with reading	9%	9%
d170 Problems with writing	6%	6%
CHAPTER 2: General tasks and demands		
d210 Undertaking a single task	22%	25%
d220 Undertaking multiple tasks	13%	16%
d230 Problems with carrying out daily routine	25%	53%
d240 Problems with handling stress and other psychological demands	44%	200%
CHAPTER 3: Communication		
d330 Problems with speaking	13%	25%
d398 Communication, other specified	6%	9%
CHAPTER 4: Mobility		
d410 Problems with changing basic body position	56%	191%
d415 Problems with maintaining a body position	22%	31%
d420 Problems with transferring oneself	19%	41%
d430 Problems with lifting and carrying objects	34%	78%
d440 Problems with fine hand use	16%	25%
d445 Problems with hand and arm use	16%	28%
d450 Problems with walking	69%	153%
d455 Moving around	56%	109%
d460 Moving around in different locations	41%	66%
d465 Problems with moving around using equipment	28%	41%
d470 Using transportation	53%	94%
d475 Driving	50%	84%
CHAPTER 5: Self-care		
d510 Problems with washing and drying oneself	50%	69%
d520 Problems with caring for body parts	6%	6%
d540 Problems with dressing	25%	34%
d550 Problems with eating	22%	34%
d560 Problems with drinking	6%	6%
d570 Problems with looking after one`s health	72%	247%

Table 7.4 Activity and participation categories identified by >5% of patients (n=50)

Activity and Participation	Relative frequency	Absolute frequency
CHAPTER 6: Domestic life		
d610 Acquiring a place to live	9%	13%
d620 Acquisition of goods and services	25%	50%
d630 Preparing meals	28%	28%
d640 Doing housework	31%	38%
d650 Caring for household objects	6%	9%
d660 Assisting others	41%	97%
CHAPTER 7: Interpersonal interactions and relationships		
d710 Basic interpersonal interactions	25%	28%
d720 Complex interpersonal interactions	16%	31%
d730 Relating with strangers	6%	9%
d740 Formal relationships	9%	9%
d750 Informal Social relationships	19%	34%
d760 Problems with family relationships	59%	184%
d770 Intimate relationships	41%	63%
CHAPTER 8: Major life areas		
d845 Acquiring, keeping and terminating a job	19%	31%
d850 Remunerative employment	84%	222%
d855 Non-remunerative employment	6%	6%
d859 Work and employment, other unspecified	6%	9%
d870 Problems with economic self-sufficiency	38%	100%
d898 Major life areas, other specified	6%	6%
CHAPTER 9: Community, social and civic life		
d910 Problems with engaging in community life	9%	9%
d920 Recreation and leisure	75%	231%
d998 Community, social and civic life	6%	6%

Twenty eight environmental factors (Table 7.5) were identified by 5% of patients. There were an equal amount of environmental barriers and facilitators although they were of different categories. Nearly half of the patients (41%) felt that *social security services, systems and policies* (e570) were a barrier to recovery. The most frequently linked environmental factors which were both barriers and facilitators were *health services, systems and policies* (e580,) *health care professionals* (e355) and p*roducts or substances for personal consumption* (e110). Health services, systems and policies (e580) (81%) was the most important environmental facilitator, followed by *health care professionals* (e355) (75%). Three categories are included in chapter 2, *natural environment and human-made changes to the environment*, although these were only reported by a small proportion of patients.

Although personal factors do not have specific categories, 29 concepts (1%) related to personal factors. These were associated with dealing with death of a relative involved in the incident, the impact of injuries on retirement, attitudes towards recovery and the content and impact of nightmares.

Table 7.5 Environmental barriers and facilitators identified by >5% of patients (n=28)

Environmental Barriers and Facilitators	Barriers		Facilitators	
	Relative frequency	Absolute frequency	Relative frequency	Absolute frequency
CHAPTER 1: Products and technology				
e110 Products for personal consumption and ingestion (food, drink and drugs)	28%	50%	44%	75%
e115 Products and technology for personal use in daily living (walking stick, bath board)	25%	47%	34%	66%
e120 Products and technology for personal indoor and outdoor mobility and transportation	19%	16%	31%	50%
e150 Design, construction and technology of building for public use	28%	44%	9%	9%
e155 Design, construction and technology of building for private use	13%	22%	6%	9%
CHAPTER 2: Natural environment and human-made changes to the environment				
e210 Physical geography	3%	3%	6%	6%
e225 Climate	13%	13%	0%	0%
e235 Human-caused events	9%	13%	0%	0%
Chapter 3: Support and relationships				
e310 Immediate family (by birth or marriage)	13%	16%	44%	66%
e320 Friends	19%	19%	50%	69%
e325 Acquaintances, peers, colleagues, neighbours and community members	0%	0%	6%	6%
e330 People in position of authority	0%	0%	22%	22%
e340 Service providers that enable work, education etc (nanny, cleaners)	3%	3%	13%	13%
e355 Health professionals (doctors, nurses, therapists)	56%	138%	75%	209%
e398 Support and relationships, other specified	9%	9%	6%	9%

Environmental Barriers and Facilitators	Barriers		Facilitators	
	Relative frequency	Absolute frequency	Relative frequency	Absolute frequency
Chapter 4: Attitudes				
e410 Attitudes of immediate family members that influence individual behaviour	6%	6%	22%	22%
e415 Attitudes of extended family members that influence behaviour or actions	0%	0%	6%	6%
e420 Attitudes of friends (specific opinions that that influence behaviour or actions)	9%	9%	31%	38%
e445 Individual attitudes of strangers	6%	13%	0%	0%
e450 Attitudes of health professionals	22%	50%	22%	50%
e460 Societal attitudes	6%	6%	3%	3%
Chapter 5: Services, systems and policies				
e535 Communication services, systems and policies	3%	3%	6%	6%
e545 Civil protection services, systems and policies	0%	0%	9%	9%
e550 Legal services, systems and policies (legislation and other law of a country)	9%	9%	0%	0%
e570 Social security, services, systems & policies (income support, unemployment)	41%	69%	19%	25%
e575 General social support services (help with shopping, housework, self-care and care)	9%	13%	9%	19%
e580 Health services, systems and policies (rehabilitation & promotion healthy lifestyle)	56%	197%	81%	247%
e590 Labour and employment services, systems and policies	19%	28%	16%	22%

7.4 Discussion

This study presents an overview of patient identified health outcomes following trauma. It demonstrated that qualitative data can be captured and transformed into categorical health concepts, using the ICF as a framework. The importance of contextual factors such as the environment and the impact on recovery is highlighted. These findings contribute to the evidence of patient important factors for recovery.

It was not the intention of the study to identify themes important to patients, but rather to investigate if patient experience can be linked to categorical health outcomes. By grouping coded data into frequency categories I was able to define typical and less typical problems faced by trauma patients. As anticipated, pain (b280), emotional consequences (b152) and walking (d450) were frequent problems of *body function* and these have also been reported in several other trauma studies (523-526). Conversely energy and drive (b130) and repair function of the skin (b820) had high frequencies but are not routinely measured in trauma literature, despite the severe impact scarring (527) and fatigue (399, 528) can have on recovery.

Handling stress and other psychological demands (d240) were identified by 44% of patients but had a very high absolute frequency (200%) emphasising the impact this had on patients' lives. The complexity of injury and recovery is further emphasised and 88% of patients reported 'being worried'. Worry was linked to the third level category (b1263) and aggregated to a second level category related to managing temperament (b126). Studies conducted in other conditions explored the relationship between 'worry' and pain (529, 530) and worry and anxiety disorders (531, 532) and established a significant negative impact of 'worry' on outcome. This was also established in studies evaluating causes of stress (533, 534) and insomnia (535, 536). This concept of 'worry' has not been previously been considered or the impact investigated in trauma. While post-traumatic stress is evaluated in some trauma outcome studies (54, 537), the routine evaluation of fatigue, worry, stress and insomnia does not occur in the trauma literature despite receiving attention in the literature related to other conditions.

Emotional aspects could not only impact on family life but also employment and leisure activities, or vice versa. Remunerative employment (d850) and recreation and leisure (d920) had the highest frequency of all linked concepts (Table 7.4). Productivity losses, due

to traumatic injuries, are estimated billions of pounds each year (538) due to demographic characteristics of trauma patients, such as age, education and compensation status (77, 539). Moreover, financial independence and employment appear to be closely related to health and well-being (540). Despite the difference in international healthcare systems, some of which have compensation systems, work remains an important outcome although absent from trauma system performance indicators (17, 154). While outcome measure, such as the SF-36 , captures aspects of social functioning, the distinct importance of leisure as part of outcome is underestimated (541).

Long term outcome, PROMs and patient satisfaction are increasingly perceived as important indicators of trauma system performance (16, 154, 448, 542, 543). Despite this there is an absence of a trauma specific measure developed through patient consultation (17, 19). The data presented captures personal experiences of trauma survivors which could assist in developing patient centred care and improve patient satisfaction. This is especially relevant for contemporary health economies as patients describe the impact that health care services, health care professional attitudes and support systems or service have on their recovery. Further, these findings add to a recent Australian study that reported patient concerns in relation to the trauma pathway and trauma system in the Victoria State, especially in relation to access to services once discharged (471).

Traditionally, HCPs consider environmental factors as access to equipment such as wheelchairs and walking aids or access to buildings and properties. However, the ICF includes services, systems and support into this concept. Legislation in the UK has ensured that disabled people can access a variety of buildings, both public and private (544) and studies have explored the effectiveness of this legislation (545). However not many studies have explored the impact of lack of access to aftercare services (154, 197, 471, 546, 547). Data clearly demonstrates that equipment and access to buildings is not of the greatest concern for trauma patients but rather access to social, rehabilitation or after care services.

Limitations

Some limitations of this study are acknowledged. Maximum variation sampling was used in an attempt to recruit a wide range of trauma patients which was achieved. However, I did not use the constant comparative method to compare responses and experiences of individuals in different groups, which could have illuminated subtle differences between patients (304). It was not the purpose of the study to explore differences between patients

or groups of patients but rather to obtain a representative sample of a very heterogeneous patient population (304).

Member checking or respondent validation had a poor response rate of 28%, however all of these respondents agreed with the transcript which contained summary findings from the interviews. Some researchers value respondent validation where others criticise it due subjective views of patients, patient burden in terms of time and the possibility upsetting the respondents (304, 548). In this study it was beneficial to gain some feedback on truthfulness of data especially due to the heterogeneous patient population which could have resulted in very diverse responses.

In terms of researcher bias, only 5% of interviews were linked by a second researcher (EC). However, 40% of linking was completed by a second researcher (EC) during the systematic review and consistency and agreement was achieved during that process reducing the need for additional review of interview data.

Conclusions

This study demonstrates that qualitative data can be collected in a heterogeneous trauma patient population, using non-traditional qualitative methods with the ICF as a reference. I was also able to demonstrate that patients have significant ongoing health issues that are not routinely measured with generic tools trauma research. In an effort to better understand the difference between patient and health care professional opinion of important health outcomes, the final chapter of this thesis will compare the data generated in Study 3A and Study 3B.

Chapter 8: IDENTIFICATION OF CANDIDATE CATEGORIES FOR AN ICF-CS FOR TRAUMA

8.1 Introduction

Throughout this thesis I have discussed the importance of accurate measurement of health outcomes in trauma in the absence of sufficient instruments. The data generated through the studies presented demonstrates that despite the ICF being unfamiliar in the trauma community it can be applied to capture patient and health care professional opinions of health outcome. However, it is not clear how HCP and patient priorities compare. A previous study used the ICF to code patient perceived goals and compared these to goals set by physiotherapists. Results showed poor agreement between patients and therapists Patients mainly focused on activity and participation goals where physiotherapists were more concerned with body functions (541). This is only one example demonstrating the necessity of considering both patient and HCP perspectives. Moreover, knowledge of patient important health outcomes will allow effective service development and resource allocation in appropriate areas of the trauma service. This knowledge could also assist in identifying training and support needs for HCPs (549) and improve communication with families (550).

The objective of this study was to compare data obtained in the previous two studies to determine the most pertinent health categories from both a patient and HCP perspective. This will enable the identification of candidate categories that can be used to develop an ICF-Core Set for trauma patients.

8.2. Methods

Data from both HCP and patient studies were combined and compared to explore agreement and differences in low to moderate frequency categories. These were >50% categories identified by HCPs in Study 3A and >5% patient categories identified in Study 3B. In order to identify the most pertinent health categories further criteria were applied to the data. For HCP data, all categories with a prevalence and significance of >70% were included. For patient data, all categories which had a patient identified relative frequency of >15% were included to present high frequency categories (399).

8.3. Results

The results of the patient interviews and HCP questionnaires were combined and compared (Tables 8.1 to 8.4). A total 192 categories with a frequency of >5% for patient data and 50% for HCP were compared. The greatest overlap between patients and HCP was found in the *body functions* (b) and *body structures* (s) component (Tables 8.1 and Table 8.2).

Seven *body functions* were considered important by HCPs, but not by patients. These were level of consciousness (b110), psychomotor problems (b147), perceptual problems (b156), blood pressure (b420), respiration functions (b440), muscle endurance (b740) and gait pattern (b770) (Table 1). No patients reported having difficulty with sequencing complex, purposeful movements (b176), problems with respiratory muscle functions (b445), problems with water, mineral and electrolyte balance (b545) or problems with involuntary movement reactions (b755) as identified by HCPs. Patients identified six additional *body function* categories but they all had a low frequency between 6% and 13% (Table 8.1). Both patients and HCP regarded temperament and personality (b126), memory (b144), emotional problems (b152) and pain (b280) as very relevant.

In terms of *body structures*, patient identified an additional eight structures (Table 8.2). Very few patients discussed issues related to body structures during the interviews and lower extremity (s750) was mentioned the most frequently (63%). The biggest discrepancy was seen for structures of the brain (s110), spinal cord and related structures (s120), structures of shoulder region (s720) and **s**tructures of areas of skin (s810). Patients identified problems with the urinary system (s610) which was not presented in the HCP questionnaire.

Table 8.1 Low to moderate frequency body function categories identified by patients and health care professionals

Body Functions	Patients Relative frequency	Patients Absolute frequency	HCP Very Common	HCP Very Important
CHAPTER 1: Mental functions				
b110 Problems with level of consciousness	9%	25%	71%	87%
b114 Problems with orientation (time, place person)	16%	25%	83%	86%
b126 Problems with temperament and personality	88%	431%	78%	87%
b130 Reduced energy and drive functions	81%	228%	87%	87%
b134 Problems with sleep	47%	131%	83%	83%
b140 Problems with attention	34%	59%	83%	84%
b144 Memory problems (short or long term memory)	56%	163%	85%	90%
b147 Psychomotor problems	9%	13%	75%	83%
b152 Emotional problems	81%	372%	86%	86%
b156 Perceptual problems	9%	19%	63%	76%
b160 Problems with thoughts or ideas	34%	72%	71%	75%
b164 Higher-level cognitive problems	28%	100%	77%	86%
b167 Problems with recognising & using signs/symbols in language	13%	38%	47%	67%
b176 Problems sequencing complex, purposeful movements	0%	0%	60%	74%
b180 Problems with self-awareness and awareness of time	56%	172%	69%	75%
CHAPTER 2: Sensory functions and pain				
b210 Problems with seeing/vision	13%	38%	47%	74%
b230 Problems with hearing problems	6%	13%	30%	57%
b235 Problems with vestibular control	13%	28%	44%	71%
b260 Problems with proprioception	3%	3%	50%	73%
b265 Problems with touch sensation (tactile/texture)	16%	22%	47%	65%
b270 Problems with sensation of temperature and other stimuli (vibration, pressure)	13%	13%	40%	54%
b279 Additional sensory functions, other specified and unspecified	6%	6%	NI†	NI†
b280 Problems with pain	81%	275%	**93%**	96%
b298 Sensory functions and pain, other specified	9%	9%	NI	NI
CHAPTER 3: Voice and speech functions				
b310 Problems with voice (quality of voice and sound)	6%	6%	42%	56%
b320 Problems with articulation	6%	6%	51%	69%
b330 Fluency and rhythm of speech functions	6%	9%	NI	NI

Presents 57 *body function* categories identified by 5% of patients and 50% of HCPs

† NI- Categories not included in HCP questionnaire

Table 8.1 continued: Low to moderate frequency body function categories identified by patients and health care professionals

Body Functions	Patients Relative frequency	Patients Absolute frequency	HCP Very Common	HCP Very Important
CHAPTER 4: Functions of the cardiovascular, haematological, immunological and respiratory systems				
b420 Problems with blood pressure	3%	3%	69%	75%
b430 Problems with haematological	13%	19%	52%	64%
b435 Problems with immune system	16%	34%	35%	61%
b440 Problems with respiration functions	13%	22%	67%	78%
b445 Problems with respiratory muscle functions	0%	0%	51%	72%
b450 Problems with additional respiratory functions	9%	13%	40%	49%
b455 Problems with exercise tolerance	41%	91%	84%	80%
b460 Sensation of cardiac and respiratory problems (palpitation and shortness of breath)	6%	6%	45%	59%
CHAPTER 5: Functions of the digestive, metabolic and endocrine systems				
b510 Problems with Ingestion (eating and drinking)	9%	25%	63%	72%
b515 Problems with digestion	6%	6%	38%	51%
b525 Problems with defecation	13%	13%	61%	67%
b530 Problems with weight maintenance	25%	28%	66%	67%
b535 Problems with sensations associated with the digestive system (bloated/indigestion)	6%	6%	38%	38%
b545 Problems with water, mineral and electrolyte balance	0%	0%	51%	62%
b550 Thermoregulatory functions	6%	13%	NI†	NI†
CHAPTER 6: Genitourinary and reproductive functions				
b610 Problems with urinary excretory functions	3%	6%	48%	59%
b620 Problems with urination	16%	19%	60%	68%
CHAPTER 7: Neuro musculoskeletal and movement-related functions				
b710 Problems with joint mobility	13%	38%	88%	92%
b715 Problems with joint stability	3%	6%	77%	84%
b720 Mobility of bone functions	6%	13%	NI	NI
b730 Problems with muscle power	28%	38%	91%	92%
b735 Problems with muscle tone	19%	22%	74%	82%
b740 Problems with muscle endurance	13%	13%	82%	78%
b755 Problems with involuntary movement reactions	0%	0%	43%	60%
b760 Problems with control of voluntary movement	9%	13%	67%	78%
b770 Problems with gait pattern (walking, running)	9%	19%	82%	85%
b780 Problems with sensations related to muscles and movement functions	6%	9%	61%	70%
CHAPTER 8: Functions of the skin and related structures				
b810 Protective functions of the skin	9%	9%	41%	57%
b820 Repair functions of the skin (wound healing)	56%	138%	64%	75%
b840 Sensation related to the skin	13%	13%	NI	NI

Presents 57 body function categories identified by 5% of patients and 50% of HCPs

† NI- Categories not included in HCP questionnaire

Table 8.2 Low to moderate frequency body structure categories identified by patients and health care professionals

Body Structures	Patient Relative frequency	Patient Absolute frequency	HCP Very Common	HCP Very Important
CHAPTER 1: Structures of the nervous system				
s110 Structures of brain	19%	50%	84%	94%
s120 Spinal cord and related structures	9%	13%	67%	92%
s130 Structures of meninges	0%	0%	40%	73%
CHAPTER 2: The eye, ear and related structures				
s220 Structure of eyeball	6%	13%	NI†	NI†
s230 Structures around eye	6%	16%	NI	NI
CHAPTER 3: Structures involved in voice and speech				
s320 Structure of the mouth	9%	16%	NI	NI
CHAPTER 4: Structures of the cardiovascular, immunological and respiratory systems				
s410 Structures of cardiovascular system	0%	0%	53%	77%
s420 Structure of immune system	6%	6%	NI	NI
s430 Structures of respiratory system	22%	59%	69%	79%
CHAPTER 5: Structures related to the digestive, metabolic and endocrine systems				
s530 Structures of stomach	16%	25%	30%	54%
s560 Structure of liver	6%	9%	NI	NI
CHAPTER 6: Structures related to genitourinary and reproductive systems				
s610 Structure of urinary system	9%	16%	NI	NI
CHAPTER 7: Structures related to movement				
s710 Structures of head and neck region	31%	66%	74%	85%
s720 Structures of shoulder region	13%	25%	72%	82%
s730 Structures of upper extremity	28%	50%	84%	87%
s740 Structures of pelvic region	16%	28%	70%	88%
s750 Structures of lower extremity	63%	159%	84%	91%
s760 Structures of trunk	25%	34%	74%	85%
s770 Additional musculoskeletal structures related to movement	6%	16%	NI	NI
CHAPTER 8: Skin and related structures				
s810 Structures of areas of skin	6%	9%	68%	73%
s820 Structure of skin glands	6%	6%	NI	NI

Presents 21 body structure categories identified by 5% of patients and 50% of HCPs

† NI- Categories not included in HCP questionnaire

There was less agreement between patients and HCPs in areas of *activities and participation* (d). Fifteen categories identified by patients in this component (d) were not included in the HCP questionnaire. In contrast, four categories (within '*Learning and applying Knowledge*, d1') were identified as important by clinicians but were rarely reported by patients. Patients prioritised tasks such as housework, shopping and helping others as part of *domestic life* (chapter 6) compared to HCPs who prioritised more items in *self-care* (chapter 5) (Table 8.3). This discrepancy could be attributed to the fact that the majority of HCPs worked in the acute setting whilst all but two patients were already back home in the community, thus prioritising different aspects of functioning as important.

Table 8.3 Low to moderate frequency activity and participation categories identified by patients and health care professionals

Activity and Participation	Patient Relative frequency	Patient Absolute frequency	HCP Very Common	HCP Very Important
CHAPTER 1: Learning and applying knowledge				
d110 Problems with watching	3%	3%	44%	64%
d115 Problems with listening	0%	0%	55%	73%
d120 Problems with other sensing	0%	0%	37%	56%
d130 Problems with copying	0%	0%	40%	58%
d135 Problems with rehearsing	0%	0%	48%	61%
d155 Problems with acquiring skills	0%	0%	66%	80%
d160 Problems with focusing attention	9%	9%	79%	87%
d163 Thinking	9%	9%	NI†	NI†
d166 Problems with reading	9%	9%	58%	70%
d170 Problems with writing	6%	6%	61%	73%
d175 Problems with problem solving	0%	0%	74%	85%
d177 Problems with making decisions	3%	3%	77%	86%
CHAPTER 2: General tasks and demands				
d210 Undertaking a single task	22%	25%	NI	NI
d220 Undertaking multiple tasks	13%	16%	NI	NI
d230 Problems with carrying out daily routine	25%	53%	84%	88%
d240 Problems with handling stress and other psychological demands	44%	200%	82%	89%
CHAPTER 3: Communication				
d310 Problems with communicating with – receiving– spoken messages	3%	3%	63%	79%
d315 Problems with communicating	0%	0%	64%	75%
d330 Problems with speaking	13%	25%	54%	74%
d335 Problems with producing nonverbal messages	0%	0%	40%	64%

Table 8.3 continued: Low to moderate frequency *activity and participation* categories identified by patients and health care professionals

Activity and Participation	Patient Relative frequency	Patient Absolute frequency	HCP Very Common	HCP Very Important
CHAPTER 3: Communication				
d350 Problems with conversation (starting, sustaining and ending a conversation)	0%	0%	59%	70%
d360 Problems with using communication devices and techniques	0%	0%	48%	66%
d398 Communication, other specified	6%	9%	NI	NI
CHAPTER 4: Mobility				
d410 Problems with changing basic body position (kneel to stand, sit to stand)	56%	191%	78%	87%
d415 Problems with maintaining a body position	22%	31%	73%	85%
d420 Problems with transferring oneself	19%	41%	80%	89%
d430 Problems with lifting and carrying objects	34%	78%	84%	85%
d440 Problems with fine hand use	16%	25%	77%	88%
d445 Problems with hand and arm use	16%	28%	69%	87%
d450 Problems with walking	69%	153%	88%	93%
d455 Moving around	56%	109%	NI	NI
CHAPTER 4: Mobility				
d460 Problems with moving around in different locations (indoor and outdoor)	41%	66%	84%	88%
d465 Problems with moving around using equipment	28%	41%	77%	87%
d470 Using transportation	53%	94%	NI†	NI†
d475 Driving	50%	84%	NI	NI
CHAPTER 5: Self-care				
d510 Problems with washing and drying oneself	50%	69%	84%	88%
d520 Problems with caring for body parts	6%	6%	80%	84%
d530 Problems with toileting	0%	0%	78%	92%
d540 Problems with dressing	25%	34%	83%	89%
d550 Problems with eating	22%	34%	72%	90%
d560 Problems with drinking	6%	6%	70%	88%
d570 Problems with looking after one`s health	72%	247%	80%	85%
CHAPTER 6: Domestic life				
d610 Acquiring a place to live	9%	13%	NI	NI
d620 Acquisition of goods and services	25%	50%	NI	NI
d630 Preparing meals	28%	28%	NI	NI
d640 Doing housework	31%	38%	NI	NI
d650 Caring for household objects	6%	9%	NI	NI
d660 Assisting others	41%	97%	NI	NI

Activity and Participation	Patient Relative frequency	Patient Absolute frequency	HCP Very Common	HCP Very Important
CHAPTER 7: Interpersonal interactions and relationships				
d710 Basic interpersonal interactions	25%	28%	NI	NI
d720 Complex interpersonal interactions	16%	31%	NI	NI
d730 Relating with strangers	6%	9%	NI	NI
d740 Formal relationships	9%	9%	NI	NI
d750 Informal Social relationships	19%	34%	NI	NI
d760 Problems with family relationships	59%	184%	83%	91%
d770 Intimate relationships	41%	63%	NI	NI
CHAPTER 8: Major life areas				
d845 Acquiring, keeping and terminating a job	19%	31%	NI	NI
d850 Remunerative employment	84%	222%	NI	NI
d855 Non-remunerative employment	6%	6%	NI	NI
d859 Work and employment, other unspecified	6%	9%	NI	NI
d870 Problems with economic self-sufficiency	38%	100%	82%	84%
d898 Major life areas, other specified	6%	6%	NI	NI
CHAPTER 9: Community, social and civic life				
d910 Problems with engaging in community life	9%	9%	81%	83%
d920 Recreation and leisure	75%	231%	NI	NI
d930 Problems with engaging in religion and spirituality	3%	3%	44%	58%
d940 Human rights	0%	0%	47%	64%
d998 Community, social and civic life	6%	6%	NI	NI

Presents 76 activity and participation categories identified by 5% of patients and 50% of HCPs
† NI- Categories not included in HCP questionnaire

Both patients and HCPs agreed on the importance of walking (d450), looking after one's health (d570) and handling stress and other psychological demands (d240). They also agreed on the importance of family relationships (d760) and patients identified other relationships such as social (d750) and intimate relationships (d770).

Remunerative employment (d850) does not occur in the Comprehensive ICF Core Set and was not included in the HCP questionnaire, although economic self-sufficiency (d870) is and was regarded very important by HCPs. This is the same for recreation and leisure (d920) which was very important for patients whereas problems with engaging in community life (d910) were identified in the HCP questionnaire.

There were also prominent discrepancies in the *environmental factors (e)* component. Environmental categories, which refer to contextual factors, are coded as barriers or facilitators to functioning. Patients identified seven additional categories but as before, these were of a low frequency (6% to 13%). The most important environmental facilitators identified by both patients and HCPs were support and attitudes of immediate family members (e310, e410), support from and attitudes of health care professionals (e355, e450) and health services, systems and policies (e580). However many patients (41%) felt that social security services, systems and policies (e570) was a barrier to recovery where HCPs actually saw these as facilitators. The third level category *drugs* (e1101) or medication was aggregated to the second level category *substances for personal consumption* (e110) which was seen as both a barrier and a facilitator for patients (Table 8.4).

Table 8.4 Low to moderate frequency *environmental barriers and facilitators* identified by patients and health care professionals

Environmental Barriers and Facilitators	Barriers			Facilitators		
	Patient Relative frequency	Patient Absolute frequency	HCP Barriers	Patient Relative frequency	Patient Absolute frequency	HCP Facilitators
CHAPTER 1: Products and technology						
e110 Products for personal consumption and ingestion (food, drink and drugs)	28%	50%	32%	44%	75%	68%
e115 Products and technology for personal use in daily living (walking stick, bath board)	25%	47%	11%	34%	66%	89%
e120 Products and technology for personal indoor and outdoor mobility and transportation	19%	16%	22%	31%	50%	78%
e125 Products and technology for communication (computers, mobile phones)	0%	0%	26%	3%	3%	74%
e150 Design, construction and technology of building for public use	28%	44%	57%	9%	9%	43%
e155 Design, construction and technology of building for private use	13%	22%	63%	6%	9%	38%
CHAPTER 2: Natural environment and human-made changes to the environment						
e210 Physical geography	3%	3%	NI†	6%	6%	NI†
e225 Climate	13%	13%	60%	0%	0%	40%
e235 Human-caused events	9%	13%	NI	NI	NI	NI
e240 Light (sunlight, candles, oil or paraffin lamps, fires and electricity)	0%	0%	36%	0%	0%	64%
e250 Sound (e.g. banging, ringing, buzzing, in any volume that is useful/distracting)	3%	6%	87%	0%	0%	13%
Chapter 3 Support and relationships						
e310 Immediate family (by birth or marriage)	13%	16%	22%	44%	66%	78%
e315 Extended family (uncles, aunts, nieces)	3%	3%	21%	0%	0%	79%
e320 Friends	19%	19%	18%	50%	69%	82%
e325 Acquaintances, peers, colleagues, neighbours and community members	0%	0%	NI	6%	6%	NI
e330 People in position of authority	0%	0%	NI	22%	22%	NI
e340 Service providers that enable work, education etc (nanny, cleaners)	3%	3%	16%	13%	13%	84%

Table8.4 continued: Low to moderate frequency *environmental barriers and facilitators* identified by patients and health care professionals

Environmental Barriers and Facilitators	Barriers			Facilitators		
	Patient Relative frequency	Patient Absolute frequency	HCP Barriers	Patient Relative frequency	Patient Absolute frequency	HCP Facilitators
Chapter 3 Support and relationships						
e355 Health professionals (doctors, nurses, therapists)	56%	138%	11%	75%	209%	89%
e360 Health related professionals (lawyers, social workers, teachers, architects)	3%	3%	16%	3%	3%	84%
e398 Support and relationships, other specified	9%	9%	NI	6%	9%	NI
Chapter 4 Attitudes						
e410 Attitudes of immediate family members that influence individual behaviour	6%	6%	39%	22%	22%	61%
e415 Attitudes of extended family members that influence behaviour or actions	0%	0%	40%	6%	6%	60%
e420 Attitudes of friends (specific opinions that that influence behaviour or actions)	9%	9%	34%	31%	38%	66%
e430 Attitudes of people in positions of authority that influence behaviour or actions	0%	0%	46%	3%	9%	54%
e440 Attitudes of personal care providers and personal assistants	0%	0%	29%	0%	0%	71%
e445 Individual attitudes of strangers	6%	13%	NI†	0%	0%	NI†
e450 Attitudes of health professionals	22%	50%	25%	22%	50%	75%
e455 Attitudes of other professionals	3%	3%	31%	3%	9%	69%
e460 Societal attitudes	6%	6%	NI	3%	3%	NI
e465 Social norms, practices and ideologies (moral and religious behaviour or etiquette)	3%	3%	53%	0%	0%	47%

Table 8.4 continued: Low to moderate *frequency environmental barriers and facilitators* identified by patients and health care professionals

Environmental Barriers and Facilitators	Barriers			Facilitators		
	Patient Relative frequency	Patient Absolute frequency	HCP Barriers	Patient Relative frequency	Patient Absolute frequency	HCP Facilitators
Chapter 5 Services, systems and policies						
e535 Communication services, systems and policies	3%	3%	NI	6%	6%	NI
e545 Civil protection services, systems and policies	0%	0%	NI	9%	9%	NI
e550 Legal services, systems and policies (legislation and other law of a country)	9%	9%	52%	0%	0%	48%
e555 Associations, memberships and organizational services (e.g. charities)	0%	0%	14%	0%	0%	86%
e570 Social security, services, systems & policies (income support, unemployment)	41%	69%	45%	19%	25%	55%
e575 General social support services (help with shopping, housework, self-care and care)	9%	13%	29%	9%	19%	71%
e580 Health services, systems and policies (rehabilitation & promotion healthy lifestyle)	56%	197%	27%	81%	247%	73%
e590 Labour and employment services, systems and policies	19%	28%	NI	16%	22%	NI

Presents 38 environmental factors identified by 5% of patients and 50% of HCPs

† NI- Categories not included in HCP questionnaire

Table 8.5 presents the final list of frequently identified categories of patients and HCPs. These are the combined categories with a relative frequency >15% for patient data and/or an average of >70% for prevalence or importance of HCPs data. The 109 categories consists of 29 *body functions*, 11 *body structures*, 41 *activity and participation* categories and 28 *environmental factors.* These was 100% agreement for *body function* and *body structure* categories. From the 41 *activity and participation* categories, 93% (n=39) were frequently identified by patients and 62% (n=27) by HCPs. *Environmental aspects* had an 88% overlap between HCPs and patients.

Table 8.5 Trauma core set candidate categories

Body Functions (n=29)
b110 Level of consciousness
b114 Orientation functions *(time, place person, post traumatic amnesia)*
b126 Temperament and personality functions *(confidence, emotional stability, optimism)*
b130 Energy and drive functions *(fatigue, disinterest)*
b134 Sleep functions *(too much/too little/altered pattern)*
b140 Attention functions *(Includes d160 Focused attention)*
b144 Memory functions *(short or long term memory)*
b147 Psychomotor problems *(coordination of sensory or cognitive processes and motor activity)*
b152 Emotional functions *(anxiety, happy, sad, appropriateness, range, regulation)*
b156 Perceptual problems *(recognizing and interpreting sensory stimuli)*
b160 Thought functions *(content, logic, control, pace)*
b164 Higher-level cognitive functions *(Includes: Problems with problem solving -d175 and Problems with making decisions -d177)*
b180 Experience of self and time functions *(self-awareness, awareness of time)*
b265 Touch function *(tactile, numb, tingling, hyperaesthesia)*
b280 Sensation of pain
b420 Blood pressure functions
b435 Immunological system functions *(infections)*
b440 Problems with respiration functions
b455 Exercise tolerance functions
b530 Weight maintenance functions
b620 Urination functions *(frequency, continence, urgency, retention)*
b710 Mobility of joint functions *(range/ease of movement)*
b715 Stability of joint functions *(structural integrity of the joints)*
b730 Muscle Power Functions
b735 Muscle tone function
b740 Muscle endurance functions
b760 Control of voluntary movement functions *(co-ordination)*
b770 Gait pattern functions
b820 Repair function of the skin *(wound healing and scars)*

Body Structures (n=11)
s110 Structures of brain
s120 Spinal cord and related structures
s430 Structures of respiratory system
s530 Structures of stomach
s710 Structures of head and neck region
s720 Structures of shoulder region
s730 Structures of upper extremity
s740 Structures of pelvic region
s750 Structures of lower extremity
s760 Structures of trunk
s810 Structures of areas of skin
Activity and Participation (n=41)
d155 Acquiring skills *(basic and complex competencies in integrated sets of actions or tasks)*
d160 Focusing attention
d175 Solving problems
d177 Making decisions *(making a choice among options, implementing the choice, and evaluating the effects of the choice)*
d210 Undertaking a single task *(carrying out simple or complex and coordinated actions related to the mental and physical components of a single task)*
d230 Carrying out daily routine
d240 Handling stress and other psychological demands
d310 Communicating with - receiving - spoken messages
d410 Changing basic body position *(kneel to stand, sit to stand)*
d415 Maintaining a body position
d420 Transferring oneself
d430 Lifting and carrying objects
d440 Fine hand use *(picking up, grasping)*
d445 Hand and arm use *(hand eye co-ordination)*
d450 Walking
d455 Moving around
d460 Moving around in different locations *(indoor and outdoor)*
d465 Moving around using equipment *(using a wheelchair or a walker)*
d470 Using transportation
d475 Driving
d510 Washing oneself
d520 Caring for body parts *(face, teeth, nails-require more than washing and drying)*
d530 Toileting
d540 Dressing
d550 Eating
d560 Drinking
d570 Looking after one's health *(balanced diet, physical activity)*
d620 Acquisition of goods and services *(selecting, producing and transporting goods and services for daily living - shopping, household items or services)*
d630 Preparing meals
d640 Doing housework

Activity and Participation (n=41)
d660 Assisting others d710 Basic interpersonal interactions *(Interacting with people in a contextually and socially appropriate manner)*
d720 Complex interpersonal interactions *(managing interactions with other people, in a contextually and socially appropriate manner - regulating emotions & impulses)*
d750 Informal Social relationships *(casual relationships with people living in the same community or residence)*
d760 Family relationships *(creating and maintaining kinship relationships, such as with members of the family)*
d770 Intimate relationships
d845 Acquiring, keeping and terminating a job
d850 Remunerative employment
d870 Economic self-sufficiency
d910 Community life *(engaging in all aspects of community social life, such as engaging in charitable organizations, service clubs)*
d920 Recreation and leisure
Environmental Barriers and Facilitators (n=26)
e110 Products for personal consumption and ingestion *(food, drink and drugs)*
e115 Products and technology for personal use in daily living *(walking stick, bath board)*
e120 Products and technology for personal indoor and outdoor mobility and transportation
e125 Products and technology for communication (computers, mobile phones)
e150 Design, construction and technology of building for public use
e155 Design, construction and technology of building for private use
e310 Immediate family - *support and relationships*
e315 Extended family -*uncles, aunts, nieces, support and relationships*
e320 Friends - *support and relationships*
e330 People in position of authority - *support and relationships*
e340 Service providers that enable work, education (nanny, cleaners, personal assistants)
e355 Health professionals *(doctors, nurses, therapists) - support and relationships*
e360 Health related professionals (lawyers, social workers, teachers, architects)
e410 Attitudes of immediate family members that influence individual behaviour or actions
e415 Attitudes of extended family members that influence behaviour or actions
e420 Attitudes of friends *(specific opinions that that influence behaviour or actions)*
e430 Attitudes of people in positions of authority that influence behaviour or actions
e440 Attitudes of personal care providers and personal assistants
e450 Attitudes of health professionals
e455 Attitudes of other professionals
e465 Social norms, practices and ideologies (moral and religious behaviour or etiquette)
e550 Legal services, systems and policies (legislation and other law of a country)
e570 Social security, services, systems & policies *(income support, tax relief)*
e575 General social support services (help with shopping, housework, self-care and care)
e580 Health services, systems and policies *(rehabilitation & promotion of a healthy lifestyle)*
e590 Labour and employment services, systems and policies

8.3 Discussion

This final study summarises important health outcomes after trauma as perceived by HCPs and patient using a modern and internationally accepted framework. Both patients and health care practitioners identify a comprehensive range of health outcomes, a large proportion of which are not captured by individual outcome measures (163).

There was substantial agreement between patients and HCPs in areas related to body structure and function. However, in areas related to activity, participation and the environment there were important categories identified by patients that are not considered by HCPs. Conversely some categories that HCPs regarded as important were not regarded as important or identified by patients. There was disagreement in some contextual factors of the environment as to whether particular factors were more likely to be facilitators or barriers to function. The International Classification of Function framework shows clear potential in its ability to capture health outcomes of trauma patients. This methodology has produced a potential core set of 109 health categories that may be used in the future to develop and ICF-CS for Trauma to evaluate health outcome of trauma patients.

Measuring health outcome of major trauma is complex, particularly because of varied injury patterns and heterogeneous patient populations. By dividing coded patient data into high and low frequency categories, and HCP questionnaire data into two categories I have defined common and important problems faced by trauma patients. This new methodology appears to provide a useful insight into patients' health outcome priorities. For example, trauma outcomes research has historically used disability measures such as the Barthel Index (337) or functional measures such as the Functional Independence Measure (155, 551, 552) which focus on aspects of self-care. Independence and safety in self-care is often a discharge requirement (553) and HCPs may spend some time getting patients independent prior to discharge (435). However, this focus may not be important for patients' during or after acute hospitalisation. This data demonstrate that work, finance and domestic tasks were of greater importance to patients than self-care activities.

The combined data, and proposed Core Set categories provides a comprehensive set of key health domains which should be considered for trauma outcomes assessment. This may focus rehabilitation priorities on patient-driven outcomes and increase engagement

between patients and HCPs (541). It will also direct and facilitate health service delivery and research (113, 554).

Existing outcome measures individually capture only a fraction of the health outcomes identified in this thesis. The systematic review (Study 2, Chapter 5) established that frequently used measures collectively assessed a maximum of 29 ICF categories (8% of the total 2nd level categories and 2% of overall ICF). The majority of these measures were developed with a narrow scope based on chronic disease models (88, 298), and not specifically for trauma (9, 20). Only one measure, the Trauma Outcomes Profile (TOP) (458) used in one study, captured 61 ICF categories (17% second level categories) although 14 of these categories referred to pain in different body structures, thus only 47 (13%) unique ICF categories. Furthermore, less than 2% of all environmental factors were captured with these outcome measures (163) despite evidence of the impact that education, access to medical insurance, trauma systems and support services has on outcome (462, 463). Thus, there is a real concern that studies using existing measures of health outcomes after trauma do not reflect the true impact of injury on patients' lives.

As an example, post-traumatic stress (PTSD) is not evaluated by existing generic outcome measures (54, 537) although PTSD scales are used intermittently in specific patient populations such as the military. In Study 3B patients did not diagnose themselves with PTSD but rather described factors that impact on their ability to manage stress after trauma. These included stress management (d240) which was the third most limiting factor in activity and participation. Patients also reported difficulty in managing temperament (b126); struggling to look after their own health (d570); and loss of productivity in terms of remunerative employment (d850). Similarly, environmental factors such as limited access to health care services, health care professional attitudes and lack of support systems or service are known to affect the recovery burden (462, 463). Assessment of these factors is clearly important in health outcome assessment, especially given the discrepancy between patient and HCP perception. Environmental factors which are barriers or facilitators to recovery should be considered in outcome evaluation. The importance of family support and relationships (d760 and e310) has been highlighted in traumatic brain injury rehabilitation (508, 555, 556). It was identified by more than half of patients and nearly 90% of HCPs despite a lack of evidence on the impact on family support and relationships in major trauma (507, 549).

Finally, work (d850) and leisure (d970) were the most important *activity and participation* categories identified by patients but are not routinely measured in trauma outcome studies despite evidence that supports the importance of these aspects. The benefit of sport and leisure activities was demonstrated in survivors of spinal cord injury (557, 558). These data demonstrate that health outcomes considered in other conditions, but not assessed by existing measures in trauma are have a significant impact on recovery.

Limitations

Patient interviews were conducted with a small sample of patients from one trauma centre in an ethnically diverse trauma centre. The majority of patients were already discharged home and this is possibly reflected in patients prioritising domestic tasks over self-care tasks. HPCs identified health outcomes which were not identified by patients and thus were excluded from the final core set. This could be attributed to the fact that the majority of HCPs were based in acute services and had knowledge of acute problems, where most patients were in the community. HPCs also have knowledge related to specific body functions such as consciousness (b110) and psychomotor problems (b147), not experiences by patients in the community or identified in such detail.

Conclusions

I have used an internationally recognised framework to describe the range and complexity of health outcomes after injury. The comprehensive assessment of the on-going health of injured patients is important for individuals, institutions, regional trauma systems, science and society. The strong consensus between an international group of trauma experts and patients presents an opportune prospect for the application of a trauma framework to collect international trauma outcome data. The results from the studies in this thesis will be presented at consensus conference. An international consensus conference will allow further discussion, debate and agreement of the principal categories to include in a Trauma Core Set. This will ensure international applicability and acceptance to ensure implementation and adherence to enable comparison of outcome after trauma.

Chapter 9: DISCUSSION

9.1 Introduction

The major findings presented in this thesis relate to the development of an evidenced based framework to improve rehabilitation and health outcome for major trauma patients. There is currently no framework internationally or in the UK guiding rehabilitation after traumatic injuries and good quality research in trauma rehabilitation is absent. Results from several individual studies were combined in this thesis to recommend a framework for improved and standardised trauma rehabilitation assessment. There are a number of factors which will affect the application of the ICF Trauma core set as a rehabilitation assessment or prescription on a large trauma population. This chapter provides a summary of the theoretical contribution, the strengths and weaknesses of the project and suggestions for future research.

9.2 Findings in relation to UK trauma networks and systems

The current structure of trauma services and trauma networks in the UK are based on the medical model with the aim of reducing mortality and improving acute care. Although the importance of rehabilitation and long term outcome is acknowledged, the evaluation and structure to capture this information remains absent. In comparison with other prevalent conditions such as stroke, there is an absence of national guidelines such as the National Institute for Health and Care Excellence Stroke guidelines (559) or the National Service Framework (NSF) for older people (560), to direct the complete pathway of care for trauma. The need to improve survival from injury in the UK was highlighted after the publication of the NCPOD report in 2007 (15) which led to the development of trauma networks. However there remains an absence of rehabilitation guidelines or standards limiting the evaluation of the effectiveness of trauma systems on quality of survival. More recently NHS England commissioned a national peer review programme (561) to evaluate performance of newly established trauma networks against nationally agreed quality measures. The rehabilitation quality measures are based on the British Society for Rehabilitation Medicine (BSRM) core standards for specialist rehabilitation in the trauma pathway (241). These guidelines are very broad and do not provide a structure to improve accuracy or effectiveness of rehabilitation assessment, despite recommending that patients with an ISS >9 require a rehabilitation prescription. The rehabilitation prescription involves completing four yes/no questions regarding physical, cognitive/emotional impairments and

psychosocial issues. Whilst these standards are a first attempt to make recommendations for trauma rehabilitation in the UK, they do not consider the patient preferences, recovery trajectory, the environment or access to services despite evidence of the significant burden of injuries (37, 38). Thus, there continues to be lack of understanding of the true rehabilitation requirements, priorities or health outcomes for trauma patients.

The framework developed throughout this thesis can specifically address some of these concerns and thus improve rehabilitation for patients within trauma networks. Figure 9.1 is an example of how the ICF can be applied as a framework for trauma service delivery and rehabilitation assessment. The combination of a complexity measure (RCS) with trauma specific ICF categories could be used as a minimum data set to identify rehabilitation needs and patient priorities. The application of this framework will allow a description of the functional state of the patients, capturing the patients' goals and experiences to enable selection of appropriate interventions. Valuable information related to environmental factors, including support systems and services will be captured which is currently absent in trauma systems. The addition of the ICF qualifier scale adds depth to the framework as the extent of the problems can be quantified and may change over time evaluated. ICF core sets have previously been applied in this way for other conditions as part of the rehabilitation cycle (101, 275) although not undertaken in trauma. The application and implementation of a Trauma core set will aid in focusing rehabilitation priorities on patients-driven outcomes and increase engagement between patients and HCPs (541). It will also direct and facilitate health service delivery and research as data on outcome will be more readily available (113, 554).

Figure 9.1 Example of the proposed ICF trauma core set for rehabilitation assessment and prescription.

REHABILITATION ASSESSMENT AND PRESCRIPTION							
Date of assessment/ date of goal set/ review date:	**Care or risk**	**Nursing**	**Medical**	**Therapy Discipline**	**Therapy Intensity**	**Equipment**	
REHABILITATION NEEDS							
REHABILITATION PROVISION							
	ICF Qualifier						
		0	**1**	**2**	**3**	**4**	
Overall goal: To return home being able to walk with assistance of one and prepare all my meals independently							
Goal 1:							
Goal 2:							
ICF CATEGORIES - USE FOR ASSESSMENT AND INTERVENTION	**ICF Qualifier**						**GOAL nr:**
Body Functions	**Problem: Y/N**	**0**	**1**	**2**	**3**	**4**	
b114 Orientation functions *(post traumatic amnesia)*	N						
b130 Energy and drive functions *(fatigue, disinterest)*	Y						
b134 Sleep functions *(too much/too little/altered pattern)*	Y						
b144 Memory functions *(short or long term memory)*	Y						
b152 Emotional functions *(anxiety, happy, sad, appropriateness, range, regulation)*	Y						
b280 Sensation of pain	Y						
b820 Repair function of the skin *(wound healing and scars)*	N						
Activity and Participation							
d230 Carrying out daily routine	Y						
d240 Handling stress and other psychological demands	Y						
d310 Communicating with - receiving - spoken messages	N						
d415 Maintaining a body position	N						
d450 Walking	Y						
d510 Washing oneself	Y						
d630 Preparing meals	Y						
d640 Doing housework	Y						
d850 Remunerative employment	Y						
d920 Recreation and leisure	Y						

	FACILITATOR					**BARRIER**			
Environmental Barriers and Facilitators (n=26)	4+	3+	2+	1+	0	-1	-2	-3	-4
e110 Products for personal consumption and ingestion									
e150 Design, construction and technology of building									
e310 Immediate family - *support and relationships*									

In addition to an improved structure for rehabilitation assessment, results from aim one demonstrated that the ISS may not be the most appropriate score to quantify patient complexity in terms of rehabilitation. A proportion of patients with high injury severity had low rehabilitation requirements and vice versa. These findings, on a small sample of trauma patients, could have implications for future funding structures. Currently Payment by Results 2013-14 (562) (Appendix 12) and the best practice tariff for trauma are based on ISS. Whilst this is helpful to determine probability of survival, funding packages should also consider rehabilitation requirements. Stroke and brain injury rehabilitation studies conducted in America demonstrated a negative impact on outcomes after the introduction of a prospective payment system (224-226). There is a complex relationship between patient and process factors in rehabilitation which needs consideration (227).

The RCS seems to provide this additional information. A larger dataset and analysis is required to further interpret the accuracy of the RCS in measuring rehabilitation needs on a larger trauma population. Together, the RCS and the ICF Trauma core set could will provide valuable information on patient complexity and rehabilitation needs and offer a structure for trauma services and networks to improve rehabilitation delivery and outcome evaluation.

The RCS studies demonstrated the applicability and acceptability of a short, effective tool to identify rehabilitation requirements of trauma patients. The studies demonstrated that additional information can be extrapolated from a complexity score to improve trauma services in terms of anticipating length of stay of patients and discharge destinations. The additional information could empower therapists and ward staff to manage workload and also manage patient expectations in terms of rehabilitation during admission and on discharge. Only one previous study, conducted in neurological rehabilitation (335), had a larger sample size than the longitudinal study completed in this thesis. The routine collection of complexity scores, in relation to injury severity and length of stay has the potential to inform trauma service evaluation to improve resource management and patient expectations and outcome. Moreover, these data fields could be included into TARN to provide more detailed information on rehabilitation requirements. Thus, overall the proposed framework (Figure 9.1) could significantly benefit the development of a structured approach to rehabilitation and rehabilitation cost analysis in trauma networks to improve patient outcome and quality of survival.

9.3 Findings in relation to MDT working and outcome measures

In terms of application of outcome measures, although the RCS-E has been recommended for use in trauma, this thesis is the first to apply and evaluate its utility in a major trauma centre in London. Both therapists and nurses participated in scoring the RSC during ward rounds. The RCS was able to categorise rehabilitation needs of patients but the rehabilitation provision was not collected. It was the first time that the RCS was used in an acute trauma setting with good participation of team members and an increased awareness of rehabilitation needs by team members. The positive attitude to using a complexity score could suggest acceptability and enthusiasm to use measures in acute trauma. This is an important reflection as there are currently no outcome measures or scores used in acute trauma. This could also pave the way for future engagement of clinical staff to improve patient centred outcome measurement such as the application of PROMS. Moreover, although rehabilitation prescriptions are recommended, the context or content has not been specified and there is very limited data available on rehabilitation requirements or provision after discharge from acute services. The initial positive staff attitudes could aid in the future submission of a rehabilitation prescription which is applicable beyond an acute environment, such as an ICF Trauma core set. The use of this would aid in linking the rehabilitation pathway where patients often feel unsupported once discharged home and thus improve patient care and satisfaction. However, staff attitudes towards using measures require further qualitative investigation to investigate overall acceptability, feasibility and usefulness. In terms of international application of the ICF; the level of participation from a wide international group of experts could indicate an international enthusiasm to improve outcome measurement and patient outcome after trauma. It also confirms the possible acceptability and comprehension of the ICF as a framework and language for use in trauma.

Despite the positive attitude of staff in terms of scale use, data from the systematic review demonstrate great variability of measures used in trauma studies. Additionally, the inconsistency in measures and the application at a variety of time point post injury limits comparison of outcome at a patient level as well as a trauma system level locally, nationally and internationally. Results revealed that only one trauma specific measure is used infrequently which is completed by HCPs rather than patient rated. This highlights the absence of trauma specific patient centred measures developed to capture the variety of problems experienced by trauma patients. Further analysis and mapping onto the ICF

confirmed that only a small proportion of health outcomes are captured by measures used most frequently in trauma studies. Additionally, the results from the on-line questionnaire suggests that HCPs recognise the impact that trauma has on function and more needs to be done to measure actual activity limitations as the measures in current use are not fit for purpose (176). This work emphasises the need to improve health outcome measurement in trauma and the need for improved outcome assessment due to the limitations of generic measures. It is also a first step in demonstrating the potential value of the ICF and its ability to capture rehabilitation and health outcomes after trauma more accurately than current measures in use.

When reflecting on the actual practicalities of implementing the ICF Trauma core set it is recognised that rehabilitation is a complex intervention which requires a cohesive MDT approach. Rehabilitation requires education and problem-solving by both patients and health care professionals to optimise a patients' activity limitations to enable social participation and wellbeing whilst reducing the stress experienced by the family or carer (182). In terms of rehabilitation and MDT working and the application of the ICF; previous studies demonstrated improved multi-disciplinary clinical reasoning where the ICF structure and language was used as part of a rehabilitation problem-solving process (288). The ICF structure and language was used to document patient perception of problems and goals and compared to health care professionals' perceived problems. This approach could facilitate patient centred goal setting and improved communication between trauma team members. The process and structure also assists in identifying which professional is responsible for a specific rehabilitation intervention, thus more effective use of staff resources. In addition, the ICF Trauma core set provides guidance on which components should be evaluated thus organising assessment to improve efficiency and clinical reasoning. This is particularly beneficial to ensure organisation of information in a common system to ensure quality and data completeness. Previous studies combined information from different sources to develop ICF based rating scales to evaluate the extent of impairments, functional limitations and environmental barriers and facilitators (184). This could be a prospective project although the ICF Trauma core set first requires implementation in the rehabilitation cycle and evaluated in trauma prior to further scale development.

9.4 Findings in relation to patient and family outcomes

A further strength of the data generated was the identification of health categories by patients and HCPs which are not routinely reported in the literature or measured in clinical practice. Issues such as cognition and fatigue are not routinely assessed (127, 491, 492) despite 80% of clinicians regarding these categories as important. There are few studies investigating the prevalence of cognitive impairment after trauma and some authors extrapolated cognitive implications from individual cognitive questions contained in outcome measures (61, 62). Some studies report that up to 65% of patients have cognitive complaints (63) where others describe patient reported cognitive impairments which include memory, attention concentration and thinking (64). When compared with patient data it is evident that these problems are present but not recognised or captured in trauma services and thus also not treated. This provides an opportunity for future investigation.

Although some studies propose to capture emotional outcome following trauma (54, 439, 440), they all use a variety of measures limiting comparison. The authors also acknowledge that despite identifying emotional problems, there are few studies investigating effective interventions to treat emotional impairments (440, 450, 471). Mental functions was the most frequently mentioned category during patient interviews and included aspects such as sleep, attention, mental fatigue, irritability, anxiety, sadness, liability, memory and concentration. Worry and handling stress and other psychological demands also had a high prevalence and although PTSD as such is not categorised by the ICF, these factors all contribute to PTSD type symptoms. No previous trauma study identified this range of mental functions and these are not routinely captured by measures. Moreover, the literature pertaining to the timeframe for the development and resolution of some of these symptoms varies (54, 59, 60) and evaluation of these should thus be considered through the patient pathway. These findings have vital importance for future assessment of patients and the development of effective mental health focused interventions to facilitate recovery. Research and development in major trauma has not previously been undertaken in this area.

In terms of physical impairments, the categories most frequently identified were pain, repair functions of the skin and exercise tolerance. Although certain types of injuries such as rib fractures or thoracotomy wounds receive good pain management interventions, (563-565), this is not always the case in other multiple injuries (566), especially not once

patients are discharged home (567). There is very limited literature related to scars, their management or impact on outcome, such as body image, after trauma (568). This is similar in terms of research related to exercise after traumatic injury and most literature focus on exercise and timing of this after brain injury (569-571).

This combination of physical, emotional and cognitive consequences directly impacts on independence in every day functional tasks and other activities related to family and social commitments (31). Patient interviews confirmed data from previous studies indicating difficulty with self-care activities and mobility (61). Whilst these activities are routinely assessed (71), domestic tasks and work related activities do not enjoy the same focus (446, 453) despite the recognised economic burden post trauma (71). The results specify patient important categories which are not routinely assessed and thus require further investigation to improve assessment and treatment to improve patient outcome over time.

Other important psycho-social aspects identified in the results relate to interpersonal relationships both in terms of participation and environmental factors. Participation in family and intimate relationships were problematic although the support from family and friends were perceived as a facilitator by both patients and HCPs. The importance of psychosocial factors and support has been discussed in previous studies (50) although there is an absence of in-depth research investigating the impact that these relationships have on recovery. Moreover, these relationships are not routinely considered in trauma assessment or rehabilitation (507, 508). Likewise, the impact of environmental factors on recovery requires further consideration well as the support and services available to facilitate employment and recreation and leisure. These unrecognised factors and the underestimated length of recovery puts extra pressure on the health and social care system as well as personal, family and societal burden (70) and the ICF Trauma core set could prompt improved awareness and consideration of these factors.

9.5 Weakness

Although much effort was made to ensure methodological rigor of studies, the work has some weaknesses which need to be considered.

The first two studies investigated the utility of the RCS v2 and the RCS-E and there were several weaknesses apparent on reflection. It is well recognised that prospective cohort

studies are resource intensive due to long recruitment periods and large samples are required to enable generalisability of data. This was a particular weakness of Study 1B and the sample size was disappointing. Collecting rehabilitation complexity data during ward rounds was particularly challenging due to time constraints. This limited the total complete admission and discharge datasets due to the high turnover of trauma patients. More comprehensive data on a larger cohort of patients could be collected in future if more resources are available. Furthermore, it became apparent at the analysis phase that it would have been beneficial to collect additional information on the *type of intervention provided* and *duration of rehabilitation session* in the prospective cohort study. These data would have enabled further analysis of the benefits of early rehabilitation; the most appropriate intervention and the most appropriate intensity in relation to rehabilitation complexity of trauma patients. This has been investigated in critical care and the benefit of early intense rehabilitation demonstrated; however, these studies did not use the RCS as a complexity scale (210, 572) but rather frequency of therapy sessions. Thus, the type of rehabilitation intervention and frequency of intervention remains vague and the heterogeneity of the patient population is frequently used to justify the absence of research (197).

A further criticism relates to the lack of additional evaluation of psychometric properties of the RCS in trauma, such as the analysis undertaken with patients with complex neurological problems (239). In general multi-disciplinary therapy teams and nurses agreed on the care, nursing, medical and therapy needs of patients using the RCS-E. However inter-rater reliability was not formally evaluated, nor was psychometric or clinimetric properties as that was not the aim of the study. Although responsiveness and utility is demonstrated by the data, the RCS-E remains un-validated in trauma and this should be investigated further.

In terms of patient interviews there are several observations. Data saturation was not formally evaluated and a pragmatic approach was taken. The sample size was based on sample sizes of previous qualitative studies where saturation was achieved. The findings mirror results of previous qualitative ICF studies were support services and systems were regarded as very important for patients already in the community (471, 517). Moreover, a large amount of categories (35%) were mentioned by less than 5% of patients which could infer that saturation was achieved.

In terms of researcher bias, only 5% of interviews were linked by a second researcher (EC). However, 40% of linking was completed by a second researcher (EC) during the systematic review and consistency and agreement was achieved during that process, reducing the need for additional review of interview data. These pragmatic measures were taken to ensure validity and data accuracy.

In general, despite these weaknesses this thesis makes a valuable contribution to this growing area of interest.

9.6 Limitations

There are several limitations that need to be considered and discussed.

Current models of rehabilitation emphasise the importance of patient centred rehabilitation (184) and engagement in goal setting. They also value the application of the ICF as a framework in terms of standardising the language used by health care professionals and the benefit of using this as part of a rehabilitation cycle. There is a significant absence in the literature demonstrating that these principles are applied in trauma rehabilitation (197). While this was an important reason for undertaking the research, the lack of structure and organisation nationally could limit the acceptance and application of an ICF Trauma core set. Additionally, there is a lack of evidence demonstrating that trauma rehabilitation actually takes place, and even less evidence for the type and frequency of intervention provided. These are important limitations which could be explored in future studies to understand knowledge and attitude to trauma rehabilitation of HCPs, trauma networks and commissioners as well as acceptability and feasibility of the use of an ICF Trauma core set.

The data from the on-line questionnaire had limitations in terms of equal representation between a variety of different HCPs and settings. The majority of participating HCPs were based in acute care settings compared to the patients interviewed that were already discharged home. Data for the on-line questionnaire was also not divided into acute and post-acute responses which may have shown a closer comparison between patient data and post-acute HCP data. The biggest discrepancy was seen in self-care and domestic tasks between HCPs and patients and this could be could be attributed to the different timeframes and settings. However, the final proposed ICF trauma candidate categories

include both self-care and domestic tasks and the relevance and importance of these could be discussed in more detail at a consensus conference.

In terms of patient interviews there were several limitations. A wide variety of patients participated in the interviews. However patients were recruited from one major trauma centre (MTC) which could be considered as a limitation. Nevertheless, the RLH has the largest catchment area of the four MTCs in London as it covers the largest network and the sample of participants with blunt and penetrating injury that were recruited are representative of an urban MTC. The maximum variation sampling was used in an attempt to recruit a wide range of trauma patients. The constant comparative method was not used to compare responses and experiences of individuals in different groups, which could have illuminated differences between patients, mechanisms of injury and time since injury (304). However, it was not the purpose of the study to explore differences between patients or groups of patients but rather to obtain a representative sample of a very heterogeneous patient population (304).

One final limitation is the absence of family and carer interviews or data. Despite the recognition of the importance of family support and relationships, the studies did not capture family, carer or significant others perspectives. This is an important limitation as trauma patients often heavily rely on support from others while in hospital and once home. This requires further exploration for integration within the ICF Trauma core set.

9.7 Suggestions for future work

There are several future opportunities to expand the work completed so far to enable application in trauma services locally and nationally.

In the first instance, the preliminary ICF Trauma core set categories could be presented at a consensus conference to approve the ICF-CS for Trauma. Once the Comprehensive and the Brief Core Sets are agreed they can be applied in a variety of ways, combined with the application of the RCS-E.

A multicentre validation study would allow application and endorsement of the ICF-CS for Trauma. The Core Set will facilitate comprehensive assessment of individual problems and needs which could assist in estimating rehabilitation potential and rehabilitation outcome

for trauma patients. The application of the ICF-CS combined with other measures of patient complexity such as the RCS-E could contribute to the development of trauma service specifications specifically aimed at improving rehabilitation and recovery of trauma patients. Moreover, a Brief Core Set for Trauma, with or without the application of ICF qualifiers, can be used as a minimum standard for rehabilitation assessment and outcome measurement, incorporating patient centred goals and outcomes. This could be considered for application as a rehabilitation prescription (Figure 9.1) to standardise these currently unstandardized prescriptions from a UK perspective (21, 241). Data obtained from these rehabilitation prescriptions can be analysed to gain a national overview of health problems experienced by trauma patients over time. Results can illuminate the extent and the prevalence of certain impairments such as cognitive functioning or fatigue. This will be a first step in moving towards the development of rehabilitation trials in trauma. Depending on the issues identified, a variety of different interventions, at differing timeframes can be investigated in randomised studies to improve outcome. Rigorous rehabilitation trials are required to determine the optimal timing and rehabilitation interventions for trauma patients. This has not been undertaken and would provide essential information to improve funding structures and trauma systems. Moreover, it will also provide an opportunity to validate the RCS-E in trauma.

There are several other research opportunities that could be explored with data obtained from the ICF Trauma core set. Several of these relate to employment, services and systems. In the UK it is currently unknown how many trauma patients experience employment issues post injury and the economic impact has not been evaluated, other than in traumatic brain injury (573). Data from the core set will identify employment issues, and barriers and facilitators related to work can then be investigated and a trial designed if deemed appropriate. The same investigation can be undertaken to review services available to patients, ease of access and overall cost benefit. This type of analysis will add to a national picture of resource use of trauma patients and enable further economic analysis.

Furthermore, additional qualitative work needs to be undertaken to investigate rehabilitation practices in trauma, including clinicians' perceptions of effective rehabilitation, acceptability of the core set and organisations attitudes to change. This type of research is essential to enable effective implementation of new systems, to overcome barriers and to ensure adoption of new processes. In addition, qualitative research exploring interpersonal relationships and support systems and the impact of trauma on the

family and significant others will enable a more holistic approach to rehabilitation and outcome management.

Due to the lack of trauma specific measures, the development of more sensitive, trauma specific measures could be considered through the application of the Rasch methodology (297). The data from validation studies could be used to investigate the possibility of constructing a clinical measure to evaluate function after trauma. Ordered responses of relevant ICF categories, as well as redundant and misfitting ICF categories can be identified by the application of the Rasch model. The majority of outcome measures in use were developed using classical test theory and consist of numerical scales. In contrast the Rasch models use principle component analysis to evaluate unidimensionality of items and are based on an interval scale (88, 256). Comprehensive analyses using modern psychometric methods such as Rasch analysis have been recommended for use to improve rating scale accuracy (88, 574, 575). Interval scales permit more accurate objective evaluation of the change in individual categories as well as overall functioning (283). The use of Rasch modelling enables more precise measurement of change in an individual's performance and capacity and also identifies redundant items to reduce participant burden (88). Moreover, it has been used to develop international item banks in America for the Patient-Reported Outcome Measurement Information System (PROMIS) (575, 576). This is used to standardise the measurement of patient reported outcome ensuring precision, flexibility and effectiveness of PROMs nationally. This model has also been applied successfully in several ICF studies (261, 299, 577) and other neurological research (578-580) and should be considered for future trauma research.

Despite initial criticism, several studies have demonstrated that the ICF does represent categories contained in QOL scales and HRQOL scales (581-583). Further work can identify the specific ICF categories in the ICF-CS for Trauma that relate to QOL to enable analysis without introducing an additional measures. These categories, once identified, could also be integrated into interval scales to operationalise QOL categories contained within the ICF Core Set (583). A combination of these with functional items will not only provide a framework for assessment but also enable accurate and consistent evaluation of change in individuals.

9.8 Conclusions

This thesis demonstrates that there continues to be profound limitations in evaluation of health and rehabilitation outcome of trauma survivors. It suggests evidence based candidate categories which could be considered as a minimum standard for assessment of rehabilitation and health outcome after trauma. Large international multi-centre studies are needed to ensure the implementation of the ICF into clinical practice. This will facilitate the evaluation of the application of the ICF in trauma and allow best practice recommendations to improve health outcome after traumatic injury.

Chapter 10 REFERENCES

1. National Audit Office N. Major trauma care in England: report by the Comptroller and Auditor General London: National Audit Office; 2010.
2. Dobscha SK, Campbell R, Morasco BJ, Freeman M, Helfand M. VA Evidence-based Synthesis Program Reports. Pain in Patients with Polytrauma: A Systematic Review. Washington (DC): Department of Veterans Affairs (US); 2008.
3. Baker SP, O'Neill B, Haddon W, Jr., Long WB. The injury severity score: a method for describing patients with multiple injuries and evaluating emergency care. J Trauma. 1974;14(3):187-96.
4. Morris JA, Jr., Sanchez AA, Bass SM, MacKenzie EJ. Trauma patients return to productivity. J Trauma. 1991;31(6):827-33; discussion 33-4.
5. Holtslag HR, Post MW, van der Werken C, Lindeman E. Return to work after major trauma. Clin Rehabil. 2007;21(4):373-83.
6. Airey CM, Chell SM, Rigby AS, Tennant A, Connelly JB. The epidemiology of disability and occupation handicap resulting from major traumatic injury. Disabil Rehabil. 2001;23(12):509-15.
7. Gabbe BJ, Sutherland AM, Williamson OD, Cameron PA. Use of health care services 6 months following major trauma. Aust Health Rev. 2007;31(4):628-32.
8. World Health Organisation W. Global Burden of Disease Geneva: WHO; 2010 [cited 2014 10th July]. Available from: http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf?ua=1.
9. Gabbe BJ, Williamson OD, Cameron PA, Dowrick AS. Choosing outcome assessment instruments for trauma registries. Acad Emerg Med. 2005;12(8):751-8.
10. Nicholl J, Turner J. Effectiveness of a regional trauma system in reducing mortality from major trauma: before and after study. BMJ. 1997;315(7119):1349-54.
11. Sampalis JS, Denis R, Lavoie A, Frechette P, Boukas S, Nikolis A, et al. Trauma care regionalization: a process-outcome evaluation. J Trauma. 1999;46(4):565-79; discussion 79-81.
12. Sampalis JS, Nathanson R, Vaillancourt J, Nikolis A, Liberman M, Angelopoulos J, et al. Assessment of mortality in older trauma patients sustaining injuries from falls or motor vehicle collisions treated in regional level I trauma centers. Ann Surg. 2009;249(3):488-95.

13. Jacob M, Kumar P. The challenge in management of hemorrhagic shock in trauma. Med J Armed Forces India. 2014;70(2):163-9.
14. Smith N, Weyman D, Findlay G, Martin I, Carter S, Utley M, et al. The management of trauma victims in England and Wales: a study by the National Confidential Enquiry into Patient Outcome and Death. Eur J Cardiothorac Surg. 36. Germany2009. p. 340-3.
15. NCEPOD. Trauma: Who cares? A report of the National Confidential Enquiry into Patient Outcome and Death: NCEPOD,; 2007 [cited 2014 29th July]. Available from: http://www.ncepod.org.uk/2007report2/Downloads/SIP_summary.pdf.
16. Cameron PA, Gabbe BJ, McNeil JJ. The importance of quality of survival as an outcome measure for an integrated trauma system. Injury. 2006;37(12):1178-84.
17. Sleat GK, Ardolino AM, Willett KM. Outcome measures in major trauma care: a review of current international trauma registry practice. Emerg Med J. 2011;28(12):1008-12.
18. NCEPOD. Trauma: Who cares? A report of the National Confidential Enquiry into Patient Outcome and Death: NCEPOD,; 2014 [cited 2014 29th July]. Available from: http://www.ncepod.org.uk/2007report2/Downloads/SIP_summary.pdf.
19. Sleat G, Willett K. Evolution of trauma care in the UK: current developments and future expectations. Injury. 2011;42(8):838-40.
20. Horwitz DA, Schuerer DJ. Trauma rehabilitation outcome scoring. Current opinion in critical care. 2008;14(4):445-50.
21. Ardolino A, Sleat G, Willett K. Outcome measurements in major trauma-Results of a consensus meeting. Injury. 2012.
22. Field M, Gold M. Summarizing Population Health: Directions for the development and application of population metrics. Washington D.C.: National Academy Press; 1998.
23. Christensen M, Ridley S, Lecky F, Munro V, Morris S. Outcomes and costs of blunt trauma in England and Wales. Critical Care. 2008;12(1):R23.
24. Glance LG, Stone PW, Mukamel DB, Dick AW. Increases in mortality, length of stay, and cost associated with hospital-acquired infections in trauma patients. Archives of Surgery. 2011;146(7):794-801.
25. Wagner AK, Fabio T, Zafonte RD, Goldberg G, Marion DW, Peitzman AB. Physical medicine and rehabilitation consultation: relationships with acute functional outcome, length of stay, and discharge planning after traumatic brain injury. Am J Phys Med Rehabil. 2003;82(7):526-36.
26. Chelvarajah R, Lee JK, Chandrasekaran S, Bavetta S. A clinical audit of neurosurgical bed usage. Br J Neurosurg. 2007;21(6):610-3; discussion 4-5.

27. Michaels AJ, Madey SM, Krieg JC, Long WB. Traditional injury scoring underestimates the relative consequences of orthopedic injury. J Trauma. 2001;50(3):389-95.
28. Melchiorre PJ, Findley T, Boda W. Functional outcome and comorbidity indexes in the rehabilitation of the traumatic versus the vascular unilateral lower limb amputee. Am J Phys Med Rehabil. 1996;75(1):9-14.
29. Perkins ZB, De'Ath HD, Sharp G, Tai NR. Factors affecting outcome after traumatic limb amputation. Br J Surg. 2012;99 Suppl 1:75-86.
30. Pezzin LE, Dillingham TR, MacKenzie EJ. Rehabilitation and the long-term outcomes of persons with trauma-related amputations. Arch Phys Med Rehabil. 2000;81(3):292-300.
31. MacKenzie EJ, Bosse MJ, Pollak AN, Webb LX, Swiontkowski MF, Kellam JF, et al. Long-term persistence of disability following severe lower-limb trauma. Results of a seven-year follow-up. J Bone Joint Surg Am. 2005;87(8):1801-9.
32. MacKenzie EJ, McCarthy ML, Ditunno JF, Forrester Staz C, Gruen GS, Marion DW, et al. Using the SF-36 for characterizing outcome after multiple trauma involving head injury. J Trauma. 2002;52(3):527-34.
33. Holtslag H, Buskens E, Rommers C, Prevo A, van CW. Long-term outcome after lower extremity injuries in severely injured patients. European Journal of Trauma. 2006;32(4):365-74.
34. Putz C, Schuld C, Gantz S, Grieser T, Akbar M, Moradi B, et al. The effect of polytrauma as a possible confounder in the outcome of monotraumatic vs polytraumatic paraplegic patients: a clinical cohort study. Spinal Cord. 2011;49(6):721-8.
35. Putz C, Schuld C, Akbar M, Grieser T, Wiedenhöfer B, Fürstenberg CH, et al. Neurological and functional recovery in multiple injured patients with paraplegia: outcome after 1 year. Journal of Trauma. 2011;70(5):1078-86.
36. Coleman WP, Geisler FH. Injury severity as primary predictor of outcome in acute spinal cord injury: retrospective results from a large multicenter clinical trial. Spine J. 2004;4(4):373-8.
37. Clay FJ, Watson WL, Newstead SV, McClure RJ. A systematic review of early prognostic factors for persisting pain following acute orthopedic trauma. Pain Res Manag. 2012;17(1):35-44.
38. Urquhart DM, Williamson OD, Gabbe BJ, Cicuttini FM, Cameron PA, Richardson MD, et al. Outcomes of patients with orthopaedic trauma admitted to level 1 trauma centres. ANZ J Surg. 2006;76(7):600-6.

39. Castillo RC, Wegener ST, Heins SE, Haythornthwaite JA, Mackenzie EJ, Bosse MJ, et al. Longitudinal relationships between anxiety, depression, and pain: Results from a two-year cohort study of lower extremity trauma patients. Pain. 2013;154(12):2860-6.
40. Jensen TS, Krebs B, Nielsen J, Rasmussen P. Immediate and long-term phantom limb pain in amputees: incidence, clinical characteristics and relationship to pre-amputation limb pain. Pain. 1985;21(3):267-78.
41. Smith DG, Ehde DM, Legro MW, Reiber GE, del Aguila M, Boone DA. Phantom limb, residual limb, and back pain after lower extremity amputations. Clin Orthop Relat Res. 1999(361):29-38.
42. Dobscha SK, Clark ME, Morasco BJ, Freeman M, Campbell R, Helfand M. Systematic review of the literature on pain in patients with polytrauma including traumatic brain injury. Pain Med. 2009;10(7):1200-17.
43. Castillo RC, MacKenzie EJ, Wegener ST, Bosse MJ, Group LS. Prevalence of chronic pain seven years following limb threatening lower extremity trauma. Pain. 2006;124(3):321-9.
44. Ebrahimzadeh MH, Fattahi AS. Long-term clinical outcomes of Iranian veterans with unilateral transfemoral amputation. Disabil Rehabil. 2009;31(22):1873-7.
45. Gironda RJ, Clark ME, Ruff RL, Chait S, Craine M, Walker R, et al. Traumatic brain injury, polytrauma, and pain: challenges and treatment strategies for the polytrauma rehabilitation. Rehabil Psychol. 2009;54(3):247-58.
46. Sigurdardottir S, Andelic N, Wehling E, Roe C, Anke A, Skandsen T, et al. Neuropsychological Functioning in a National Cohort of Severe Traumatic Brain Injury: Demographic and Acute Injury-Related Predictors. J Head Trauma Rehabil. 2014.
47. Brenner LA. Neuropsychological and neuroimaging findings in traumatic brain injury and post-traumatic stress disorder. Dialogues Clin Neurosci. 2011;13(3):311-23.
48. Dacey R, Dikmen S, Temkin N, McLean A, Armsden G, Winn HR. Relative effects of brain and non-brain injuries on neuropsychological and psychosocial outcome. J Trauma. 1991;31(2):217-22.
49. Ponzer S, Bergman B, Brismar B, Johansson SE. Women and injuries--factors influencing recovery. Women Health. 1997;25(3):47-62.
50. Halcomb E, Daly J, Davidson P, Elliott D, Griffiths R. Life beyond severe traumatic injury: an integrative review of the literature. Aust Crit Care. 2005;18(1):17-8, 20-4.
51. Koren D, Arnon I, Klein E. Acute stress response and posttraumatic stress disorder in traffic accident victims: a one-year prospective, follow-up study. Am J Psychiatry. 1999;156(3):367-73.

52. Michaels AJ, Michaels CE, Moon CH, Smith JS, Zimmerman MA, Taheri PA, et al. Posttraumatic stress disorder after injury: impact on general health outcome and early risk assessment. J Trauma. 1999;47(3):460-6; discussion 6-7.

53. Olofsson E, Bunketorp O, Andersson AL. Children and adolescents injured in traffic--associated psychological consequences: a literature review. Acta Paediatr. 2009;98(1):17-22.

54. Soberg HL, Bautz-Holter E, Roise O, Finset A. Mental health and posttraumatic stress symptoms 2 years after severe multiple trauma: self-reported disability and psychosocial functioning. Archives of Physical Medicine & Rehabilitation. 2010;91(3):481-9.

55. Aaron DL, Fadale PD, Harrington CJ, Born CT. Posttraumatic stress disorders in civilian orthopaedics. J Am Acad Orthop Surg. 2011;19(5):245-50.

56. Flett RA, Kazantzis N, Long NR, MacDonald C, Millar M. Traumatic events and physical health in a New Zealand community sample. J Trauma Stress. 2002;15(4):303-12.

57. Kazantzis N, Kennedy-Moffat J, Flett RA, Petrik AM, Long NR, Castell B. Predictors of Chronic Trauma-Related Symptoms in a Community Sample of New Zealand Motor Vehicle Accident Survivors. Culture Medicine and Psychiatry. 2012;36(3):442-64.

58. D'Andrea W, Sharma R, Zelechoski AD, Spinazzola J. Physical health problems after single trauma exposure: when stress takes root in the body. J Am Psychiatr Nurses Assoc. 2011;17(6):378-92.

59. Zatzick DF, Jurkovich GJ, Fan MY, Grossman D, Russo J, Katon W, et al. Association between posttraumatic stress and depressive symptoms and functional outcomes in adolescents followed up longitudinally after injury hospitalization. Arch Pediatr Adolesc Med. 2008;162(7):642-8.

60. Zatzick DF, Kang SM, Hinton WL, Kelly RH, Hilty DM, Franz CE, et al. Posttraumatic concerns: a patient-centered approach to outcome assessment after traumatic physical injury. Med Care. 2001;39(4):327-39.

61. Soberg HL, Bautz-Holter E, Roise O, Finset A. Long-term multidemensional functional consequences of severe multiple injuries two years after trauma: a prospective longitudinal cohort study. Journal of Trauma. 2007;62(2):461-71.

62. Vles WJ, Steyerberg EW, Essink-Bot ML, van Beeck EF, Meeuwis JD, Leenen LP. Prevalence and determinants of disabilities and return to work after major trauma. J Trauma. 2005;58(1):126-35.

63. Holtslag HR, van EFE, Lindeman E, Leenen LP. Determinants of long-term functional consequences after major trauma. Journal of Trauma. 2007;62(4):919-28.

64. Sluys K, Haggmark T, Iselius L. Outcome and quality of life 5 years after major trauma. J Trauma. 2005;59(1):223-32.

65. Clay FJ, Fitzharris M, Kerr E, McClure RJ, Watson WL. The association of social functioning, social relationships and the receipt of compensation with time to return to work following unintentional injuries to Victorian workers. J Occup Rehabil. 2012;22(3):363-75.

66. Clay FJ, Newstead SV, Watson WL, Ozanne-Smith J, McClure RJ. Bio-psychosocial determinants of time lost from work following non life threatening acute orthopaedic trauma. BMC Musculoskelet Disord. 2010;11:6.

67. Gore FM, Bloem PJN, Patton GC, Ferguson J, Joseph V, Coffey C, et al. Global burden of disease in young people aged 10–24 years: a systematic analysis. The Lancet.377(9783):2093-102.

68. Gore FM, Bloem PJ, Patton GC, Ferguson J, Joseph V, Coffey C, et al. Global burden of disease in young people aged 10-24 years: a systematic analysis. Lancet. 2011;377(9783):2093-102.

69. McHorney CA, Ware JE, Jr., Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care. 1993;31(3):247-63.

70. Brenneman FD, Redelmeier DA, Boulanger BR, McLellan BA, Culhane JP. Long-term outcomes in blunt trauma: who goes back to work? J Trauma. 1997;42(5):778-81.

71. Polinder S, van EFE, Essink-Bot ML, Toet H, Looman CW, Mulder S, et al. Functional outcome at 2.5, 5, 9, and 24 months after injury in the Netherlands. Journal of Trauma. 2007;62(1):133-42.

72. Meerding WJ, Looman CW, Essink-Bot ML, Toet H, Mulder S, van Beeck EF. Distribution and determinants of health and work status in a comprehensive population of injury patients. J Trauma. 2004;56(1):150-61.

73. Christensen MC, Banner C, Lefering R, Vallejo-Torres L, Morris S. Quality of Life After Severe Trauma: Results From the Global Trauma Trial With Recombinant Factor VII. Journal of Trauma. 2011;70(6):1524-32.

74. Harris IA, Young JM, Rae H, Jalaludin BB, Solomon MJ. Predictors of general health after major trauma. J Trauma. 2008;64(4):969-74.

75. Aitken LM, Davey TM, Ambrose J, Connelly LB, Swanson C, Bellamy N. Health outcomes of adults 3 months after injury. Injury. 2007;38(1):19-26.

76. Holbrook TL, Anderson JP, Sieber WJ, Browner D, Hoyt DB. Outcome after major trauma: discharge and 6-month follow-up results from the Trauma Recovery Project. J Trauma. 1998;45(2):315-23; discussion 23-4.

77. Gabbe BJ, Harris IA, Collie A, Cameron PA. Does access to compensation have an impact on recovery outcomes after injury? Comment. Med J Aust. 2010;193(3):188; author reply 90.

78. Grant GM, O'Donnell ML, Spittal MJ, Creamer M, Studdert DM. Relationship between stressfulness of claiming for injury compensation and long-term recovery: a prospective cohort study. JAMA Psychiatry. 2014;71(4):446-53.

79. World Health Organisation W. International Statistical Classification of Diseases and Related HealthProblems Geneva: World Health Organisation; 2010 [cited 2014 27th August]. 10th:[Available from: http://www.who.int/classifications/icd/ICD10Volume2_en_2010.pdf?ua=1.

80. Iezzoni LI, Greenberg MS. Capturing and classifying functional status information in administrative databases. (0195-8631 (Print)).

81. Ustün TB, Chatterji S, Kostansjek N, Bickenbach J. WHO's ICF and functional status information in health records. Health Care Financ Rev. 2003;24(3):77-88.

82. World Health Organisation W. World Report on Disability Geneva: WHO; 2011 [cited 2014 10th July]. Available from: http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf?ua=1.

83. Masala C, Petretto DR. From disablement to enablement: conceptual models of disability in the 20th century. Disabil Rehabil. 2008;30(17):1233-44.

84. Kearney PM, Pryor J. The International Classification of Functioning, Disability and Health (ICF) and nursing. J Adv Nurs. 2004;46(2):162-70.

85. Bowling A. *Measuring Health- a review of quality of life measurement scales*. 3rd ed. Buckingham: Open University Press; 2005.

86. Whalley-Hammell K. Perspectives on Disability and Rehabilitation: Contesting Assumptions, Challenging Practice. London: Churchill Livingston; 2006.

87. Imrie R. Rethinking the relationships between disability, rehabilitation, and society. Disabil Rehabil. 1997;19(7):263-71.

88. Hobart JC, Cano SJ, Zajicek JP, Thompson AJ. Rating scales as outcome measures for clinical trials in neurology: problems, solutions, and recommendations. Lancet Neurol. 2007;6(12):1094-105.

89. Gzil F, Lefeve C, Cammelli M, Pachoud B, Ravaud JF, Leplege A. Why is rehabilitation not yet fully person-centred and should it be more person-centred? Disabil Rehabil. 29. England2007. p. 1616-24.

90. Oliver M. *Understanding Disability: From Theory to Practice*. 2nd ed. Basingstoke: Palgrave Macmillan; 2009.

91. Hughes B, Paterson K. The Social Model of Disability and the disappearing body: Towards a sociology of impairment. Disability and society. 1997;12(3):325-40.

92. Nagi SZ. A study in the evaluation of disability and rehabilitation potential: Concepts, methods and procedures. Am J Public Health Nations Health. 1964;54:1568-79.

93. Verbrugge LM, Jette AM. The disablement process. Soc Sci Med. 1994;38(1):1-14.

94. Jette AM. Toward a common language for function, disability, and health. Phys Ther. 2006;86(5):726-34.

95. IOM IoM. The Future of Disability in America. Washington: DC: The National Academies Press; 2007.

96. Jette AM. Toward a common language of disablement. J Gerontol A Biol Sci Med Sci. 64. United States2009. p. 1165-8.

97. Fawcett A. Principles of Assessment and Outcome Measurement for Occupational Therapists and Physiotherapists: Theory, Skills and Application. 1st ed. Chichester: John Wiley and Sons Ltd; 2007.

98. Bickenbach JE, Chatterji S, Badley EM, Ustun TB. Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. Soc Sci Med. 1999;48(9):1173-87.

99. World Health Organisation W. Towards a common language for function, disability and health ICF Geneva: World Helath Organisation; 2002 [cited 2014 08/07/2014]. Available from: http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf.

100. Schliehe F. [The ICF classification system--a problem oriented inventory on behalf of the German Society of Rehabilitation Sciences]. Rehabilitation (Stuttg). 2006;45(5):258-71.

101. Rauch A, Cieza A, Stucki G. How to apply the International Classification of Functioning, Disability and Health (ICF) for rehabilitation management in clinical practice. Eur J Phys Rehabil Med. 2008;44(3):329-42.

102. Stucki G, Cieza A. The International Classification of Functioning, Disability and Health (ICF) in physical and rehabilitation medicine. Eur J Phys Rehabil Med. 2008;44(3):299-302.

103. Schuntermann MF. The implementation of the International Classification of Functioning, Disability and Health in Germany: experiences and problems. Int J Rehabil Res. 2005;28(2):93-102.

104. Tempest S, Harries P, Kilbride C, De Souza L. To adopt is to adapt: the process of implementing the ICF with an acute stroke multidisciplinary team in England. Disabil Rehabil. 2012;34(20):1686-94.

105. Sanches-Ferreira M, Simeonsson RJ, Silveira-Maia M, Alves S, Tavares A, Pinheiro S. Portugal's special education law: implementing the International Classification of Functioning, Disability and Health in policy and practice. Disabil Rehabil. 2013;35(10):868-73.

106. Maxwell G, Koutsogeorgou E. Using social capital to construct a conceptual International Classification of Functioning, Disability, and Health Children and Youth version-based framework for stronger inclusive education policies in Europe. Am J Phys Med Rehabil. 2012;91(13 Suppl 1):S118-23.

107. Chiu WT, Yen CF, Teng SW, Liao HF, Chang KH, Chi WC, et al. Implementing disability evaluation and welfare services based on the framework of the International Classification of Functioning, Disability and Health: experiences in Taiwan. BMC Health Serv Res. 2013;13:416.

108. Crawford R. Healthism and the medicalization of everyday life. Int J Health Serv. 1980;10(3):365-88.

109. Kronenfeld JJ. Changing conceptions of health and life course concepts. Health (London). 2006;10(4):501-17.

110. Hoffmann I. Transcending reductionism in nutrition research. Am J Clin Nutr. 2003;78(3 Suppl):514s-6s.

111. Hoffmann M, Lefering R, Gruber-Rathmann M, Rueger JM, Lehmann W, Trauma RS. The impact of BMI on polytrauma outcome. Injury. 2012;43(2):184-8.

112. Sweeney K, Kernick D. Clinical evaluation: constructing a new model for post-normal medicine. J Eval Clin Pract. 2002;8(2):131-8.

113. Wright JWRWJR. Development and importance of health needs assessment. BMJ. 1998;316(7140):1310-3.

114. Brohi K, Cohen MJ, Davenport RA. Acute coagulopathy of trauma: mechanism, identification and effect. Curr Opin Crit Care. 2007;13(6):680-5.

115. Robins RJ, Porta CR, Eastridge BJ, Holcomb JB, Martin MJ. Implications of Humanitarian Orthopaedic Surgery in a Combat Zone: Operation Enduring Freedom and Iraqi Freedom Experience. J Surg Orthop Adv. 2014;23(3):129-35.

116. Bowling A. *Research methods in health: Investigating health and health services*. *Research methods in health: Investigating health and health services*. Maidenhead: Open University Press; 2004. p. 257-72.

117. Kreder H. (i) Importance of outcome research after major trauma. Current Orthopaedics. 2003;17(5):331-4.

118. Stucki G, Cieza A, Ewert T, Kostanjsek N, Chatterji S, Ustün TB. Application of the International Classification of Functioning, Disability and Health (ICF) in clinical practice. Disabil Rehabil. 2002;24(5):281-2.

119. WHOQOL G. Development of the WHOQoL: Rationale and current status. International Journal of Mental Health. 1994;23:24-57.

120. Raftery J. How should we value future health? Was NICE right to change? Value Health. 2013;16(5):699-700.

121. Rawlins M, Dillon A. Cost-effectiveness considerations at NICE. Lancet. 372. England2008. p. 1302.

122. Holtslag HR, van Beeck EF, Lichtveld RA, Leenen LP, Lindeman E, van der Werken C. Individual and population burdens of major trauma in the Netherlands. Bull World Health Organ. 2008;86(2):111-7.

123. Lyons RA, Kendrick D, Towner EM, Christie N, Macey S, Coupland C, et al. Measuring the population burden of injuries--implications for global and national estimates: a multi-centre prospective UK longitudinal study. PLoS Med. 2011;8(12):e1001140.

124. Polinder S, Meerding WJ, Mulder S, Petridou E, van Beeck E, Group ER. Assessing the burden of injury in six European countries. Bull World Health Organ. 2007;85(1):27-34.

125. Krug EG, Sharma GK, Lozano R. The global burden of injuries. Am J Public Health. 2000;90(4):523-6.

126. EuroQol--a new facility for the measurement of health-related quality of life. The EuroQol Group. Health Policy. 1990;16(3):199-208.

127. Derrett S, Black J, Herbison GP. Outcome after injury-a systematic literature search of studies using the EQ-5D. Journal of Trauma - Injury, Infection and Critical Care. 2009;67(4):883-90.

128. Jenkinson C, Wright L, Coulter A. The SF 36 health survey questionnaire. ...if used within its limits. BMJ. 1993;307(6901):449.

129. Teasdale GM, Pettigrew LE, Wilson JT, Murray G, Jennett B. Analyzing outcome of treatment of severe head injury: a review and update on advancing the use of the Glasgow Outcome Scale. J Neurotrauma. 1998;15(8):587-97.

130. Pettigrew LE, Wilson JT, Teasdale GM. Assessing disability after head injury: improved use of the Glasgow Outcome Scale. J Neurosurg. 1998;89(6):939-43.

131. Michener LA. Patient- and clinician-rated outcome measures for clinical decision making in rehabilitation. J Sport Rehabil. 2011;20(1):37-45.

132. Kramer AM. Rehabilitation care and outcomes from the patient's perspective. Med Care. 1997;35(6 Suppl):JS48-57; discussion JS8-63.

133. Wright JG. Outcomes research: what to measure. World J Surg. 1999;23(12):1224-6.
134. Black N. Patient reported outcome measures could help transform healthcare. Bmj. 2013;346:f167.
135. Haywood KL. Patient-reported outcome I: measuring what matters in musculoskeletal care. Musculoskeletal Care. 2006;4(4):187-203.
136. Wylde V, Learmonth ID, Cavendish VJ. The Oxford hip score: the patient's perspective. Health Qual Life Outcomes. 2005;3:66.
137. Thorborg K, Roos EM, Bartels EM, Petersen J, Holmich P. Validity, reliability and responsiveness of patient-reported outcome questionnaires when assessing hip and groin disability: a systematic review. Br J Sports Med. 2010;44(16):1186-96.
138. Champion HR, Copes WS, Sacco WJ, Lawnick MM, Keast SL, Bain LW, Jr., et al. The Major Trauma Outcome Study: establishing national norms for trauma care. J Trauma. 1990;30(11):1356-65.
139. Wardrope J, Cross SF, Fothergill DJ. One year's experience of major trauma outcome study methodology. Bmj. 1990;301(6744):156-9.
140. Yates DW, Woodford M, Hollis S. Preliminary analysis of the care of injured patients in 33 British hospitals: first report of the United Kingdom major trauma outcome study. Bmj. 1992;305(6856):737-40.
141. Davis JW, Hoyt DB, McArdle MS, Mackersie RC, Eastman AB, Virgilio RW, et al. An analysis of errors causing morbidity and mortality in a trauma system: a guide for quality improvement. J Trauma. 1992;32(5):660-5; discussion 5-6.
142. Engel DC. Standardizing data collection in severe trauma: call for linking up. Crit Care. 2012;16(1):105.
143. Trunkey DD. The value of trauma centers. Bull Am Coll Surg. 1982;67(10):5-7.
144. West JG, Cales RH, Gazzaniga AB. Impact of regionalization. The Orange County experience. Arch Surg. 1983;118(6):740-4.
145. Albert J, Phillips H. Trauma care systems in the United Kingdom. Injury. 2003;34(9):728-34.
146. Mullins RJ, Mann NC. Population-based research assessing the effectiveness of trauma systems. J Trauma. 1999;47(3 Suppl):S59-66.
147. Mann NC, Mullins RJ, MacKenzie EJ, Jurkovich GJ, Mock CN. Systematic review of published evidence regarding trauma system effectiveness. J Trauma. 1999;47(3 Suppl):S25-33.

148. MacKenzie EJ, Rivara FP, Jurkovich GJ, Nathens AB, Frey KP, Egleston BL, et al. A national evaluation of the effect of trauma-center care on mortality. N Engl J Med. 2006;354(4):366-78.

149. Institute of Medicine Committee on Quality of Health Care in A. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US). Copyright 2001 by the National Academy of Sciences. All rights reserved.; 2001.

150. Stelfox HT, Boyd JM, Straus SE, Gagliardi AR. Developing a patient and family-centred approach for measuring the quality of injury care: a study protocol. BMC Health Serv Res. 2013;13:31.

151. Evans C, Howes D, Pickett W, Dagnone L. Audit filters for improving processes of care and clinical outcomes in trauma systems. Cochrane Database Syst Rev. 2009(4):Cd007590.

152. Ringdal KG, Lossius HM, Jones JM, Lauritsen JM, Coats TJ, Palmer CS, et al. Collecting core data in severely injured patients using a consensus trauma template: an international multicentre study. Crit Care. 15. England2011. p. R237.

153. McDermott FT. Trauma audit and quality improvement. Aust N Z J Surg. 1994;64(3):147-54.

154. Gruen RL, Gabbe BJ, Stelfox HT, Cameron PA. Indicators of the quality of trauma care and the performance of trauma systems. Br J Surg. 2012;99 Suppl 1:97-104.

155. Dodds TA, Martin DP, Stolov WC, Deyo RA. A validation of the functional independence measurement and its performance among rehabilitation inpatients. Arch Phys Med Rehabil. 1993;74(5):531-6.

156. Levin HS, Boake C, Song J, McCauley S, Contant C, Diaz-Marchan P, et al. Validity and sensitivity to change of the extended Glasgow Outcome Scale in mild to moderate traumatic brain injury. J Neurotrauma. 2001;18(6):575-84.

157. Wilson JT, Pettigrew LE, Teasdale GM. Structured interviews for the Glasgow Outcome Scale and the extended Glasgow Outcome Scale: guidelines for their use. J Neurotrauma. 1998;15(8):573-85.

158. Gabbe BJ, Sutherland AM, Hart MJ, Cameron PA. Population-based capture of long-term functional and quality of life outcomes after major trauma: the experiences of the Victorian State Trauma Registry. J Trauma. 2010;69(3):532-6; discussion 6.

159. Trauma Audit Research Network T. Trauma Audit Research Network Procedures Manual Manchester: Trauma Audit Research Network; 2011. Available from: https://www.tarn.ac.uk/content/downloads/53/Full%20Procedures%20June%202011.pdf

160. Bouillon B, Kreder HJ, Eypasch E, Holbrook TL, Mayou R, Nast-Kolb D, et al. Quality of life in patients with multiple injuries--basic issues, assessment, and recommendations. Restor Neurol Neurosci. 2002;20(3-4):125-34.

161. Van Beeck EF, Larsen CF, Lyons RA, Meerding WJ, Mulder S, Essink-Bot ML. Guidelines for the conduction of follow-up studies measuring injury-related disability. J Trauma. 2007;62(2):534-50.

162. Boyle MH, Furlong W, Feeny D, Torrance GW, Hatcher J. Reliability of the Health Utilities Index--Mark III used in the 1991 cycle 6 Canadian General Social Survey Health Questionnaire. Qual Life Res. 1995;4(3):249-57.

163. Hoffman K, Cole E, Playford ED, Grill E, Soberg HL, Brohi K. Health Outcome after Major Trauma: What Are We Measuring? PLoS One. 2014;9(7):e103082.

164. Trauma Audit and Research Network T, Group. CI. Systematic Review of Major Trauma Outcome Measures. 2011.

165. Chawda MN, Hildebrand F, Pape HC, Giannoudis PV. Predicting outcome after multiple trauma: which scoring system? Injury. 2004;35(4):347-58.

166. Dowrick AS, Gabbe BJ, Williamson OD, Cameron PA. Outcome instruments for the assessment of the upper extremity following trauma: a review. Injury. 2005;36(4):468-76.

167. Derrett S, Black J, Herbison GP. Outcome After Injury-A Systematic Literature Search of Studies Using the EQ-5D. The Journal of Trauma and Acute Care Surgery. 2009;67(4):883-90 10.1097/TA.0b013e3181ae6409.

168. Black JA, Herbison GP, Lyons RA, Polinder S, Derrett S. Recovery after injury: an individual patient data meta-analysis of general health status using the EQ-5D. J Trauma. 2011;71(4):1003-10.

169. Polinder S, Haagsma JA, Belt E, Lyons RA, Erasmus V, Lund J, et al. A systematic review of studies measuring health-related quality of life of general injury populations. BMC Public Health. 2010;10:783.

170. Schwartz I, Tsenter J, Shochina M, Shiri S, Kedary M, Katz-Leurer M, et al. Rehabilitation outcomes of terror victims with multiple traumas. Archives of Physical Medicine & Rehabilitation. 2007;88(4):440-9.

171. Siddharthan K, Scott S, Bass E, Nelson A. Rehabilitation outcomes for veterans with polytrauma treated at the Tampa VA. Rehabilitation Nursing. 2008;33(5):221-6.

172. Laxe S, Tschiesner U, Zasler N, López-Blazquez R, Tormos JM, Bernabeu M. What domains of the International Classification of Functioning, Disability and Health are covered by the most commonly used measurement instruments in traumatic brain injury research? Clin Neurol Neurosurg. 2012;114(6):645-50.

173. de Guise E, LeBlanc J, Dagher J, Tinawi S, Lamoureux J, Marcoux J, et al. Characteristics of patients with acute traumatic brain injury discharged against medical advice in a Level 1 urban trauma centre. Brain Inj. 2014:1-7.

174. Cullen N, Krakowski A, Taggart C. Functional independence measure at rehabilitation admission as a predictor of return to driving after traumatic brain injury. Brain Inj. 2014;28(2):189-95.

175. Nichol AD, Higgins AM, Gabbe BJ, Murray LJ, Cooper DJ, Cameron PA. Measuring functional and quality of life outcomes following major head injury: common scales and checklists. Injury. 2011;42(3):281-7.

176. Williamson OD, Gabbe BJ, Sutherland AM, Wolfe R, Forbes AB, Cameron PA. Comparing the responsiveness of functional outcome assessment measures for trauma registries. J Trauma. 2011;71(1):63-8.

177. MacKenzie EJ, Damiano A, Miller T, Luchter S. The development of the Functional Capacity Index. J Trauma. 1996;41(5):799-807.

178. Schluter PJ, Neale R, Scott D, Luchter S, McClure RJ. Validating the functional capacity index: a comparison of predicted versus observed total body scores. J Trauma. 58. United States2005. p. 259-63.

179. Wade DT, de Jong BA. Recent advances in rehabilitation. BMJ. 2000;320(7246):1385-8.

180. Siegert RJ, Ward T, Playford ED. Human rights and rehabilitation outcomes. Disabil Rehabil. 2010;32(12):965-71.

181. Wade DT, Halligan P. New wine in old bottles: the WHO ICF as an explanatory model of human behaviour. Clin Rehabil. 2003;17(4):349-54.

182. Wade DT. Describing rehabilitation interventions. Clin Rehabil. 2005;19(8):811-8.

183. Levack WM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. Disabil Rehabil. 2010;32(12):986-99.

184. Dean S, Siegert R, Taylor W. Interprofessional Rehabilitation: A person-centred approach. Oxford: Wiley-Blackwell; 2012.

185. Organisation WH. WHO Guidelines on Health-Related Rehabilitation (Rehabilitation Guidelines). Geneva: World Health Organisation, 2012.

186. Leplege A, Gzil F, Cammelli M, Lefeve C, Pachoud B, Ville I. Person-centredness: conceptual and historical perspectives. Disabil Rehabil. 29. England2007. p. 1555-65.

187. Sandvin J. Rehabilitation: A Norwegian expert asks if it is still a useful concept? On-line: *Disability World* 15 September/October, unpaged; 2002 [cited 2015 January]. Available from: http://www.disabilityworld.org/09-10_02/il/useful.shtml.

188. Knudson MM, Ikossi DG. Venous thromboembolism after trauma. Curr Opin Crit Care. 2004;10(6):539-48.

189. Ho KM, Tan JA, Burrell M, Rao S, Misur P. Venous thrombotic, thromboembolic, and mechanical complications after retrievable inferior vena cava filters for major traumadagger. Br J Anaesth. 2014.

190. Sullivan MP, Torres SJ, Mehta S, Ahn J. Heterotopic ossification after central nervous system trauma: A current review. Bone Joint Res. 2013;2(3):51-7.

191. Cipriano CA, Pill SG, Keenan MA. Heterotopic ossification following traumatic brain injury and spinal cord injury. J Am Acad Orthop Surg. 2009;17(11):689-97.

192. Joseph B, Pandit V, Zangbar B, Kulvatunyou N, Hashmi A, Green DJ, et al. Superiority of Frailty Over Age in Predicting Outcomes Among Geriatric Trauma Patients: A Prospective Analysis. JAMA Surg. 2014.

193. Foruria AM, Augustin S, Morrey BF, Sanchez-Sotelo J. Heterotopic ossification after surgery for fractures and fracture-dislocations involving the proximal aspect of the radius or ulna. J Bone Joint Surg Am. 2013;95(10):e66.

194. Buntin MB, Garten AD, Paddock S, Saliba D, Totten M, Escarce JJ. How much is postacute care use affected by its availability? Health Serv Res. 2005;40(2):413-34.

195. Zatzick D, Rivara F, Jurkovich G, Russo J, Trusz SG, Wang J, et al. Enhancing the population impact of collaborative care interventions: mixed method development and implementation of stepped care targeting posttraumatic stress disorder and related comorbidities after acute trauma. General Hospital Psychiatry. 2011;33(2):123-34.

196. Schneidert M, Hurst R, Miller J, Ustun B. The role of environment in the International Classification of Functioning, Disability and Health (ICF). Disabil Rehabil. 2003;25(11-12):588-95.

197. Khan F, Amatya B, Hoffman K. Systematic review of multidisciplinary rehabilitation in patients with multiple trauma. Br J Surg. 2012;99 Suppl 1:88-96.

198. Taylor NF, Brusco NK, Watts JJ, Shields N, Peiris C, Sullivan N, et al. A study protocol of a randomised controlled trial incorporating a health economic analysis to investigate if additional allied health services for rehabilitation reduce length of stay without compromising patient outcomes. BMC Health Serv Res. 2010;10:308.

199. Connolly B, Douiri A, Steier J, Moxham J, Denehy L, Hart N. A UK survey of rehabilitation following critical illness: implementation of NICE Clinical Guidance 83 (CG83) following hospital discharge. BMJ Open. 2014;4(5):e004963.

200. Burtin C, Clerckx B, Robbeets C, Ferdinande P, Langer D, Troosters T, et al. Early exercise in critically ill patients enhances short-term functional recovery. Crit Care Med. 2009;37(9):2499-505.

201. Salter K, Jutai J Fau - Hartley M, Hartley M Fau - Foley N, Foley N Fau - Bhogal S, Bhogal S Fau - Bayona N, Bayona N Fau - Teasell R, et al. Impact of early vs delayed admission to rehabilitation on functional outcomes in persons with stroke. (1650-1977 (Print)).

202. Roth EJ, Lovell L, Harvey RL, Bode RK. Delay in transfer to inpatient stroke rehabilitation: the role of acute hospital medical complications and stroke characteristics. Top Stroke Rehabil. 2007;14(1):57-64.

203. Wang H, Camicia M Fau - Terdiman J, Terdiman J Fau - Hung Y-Y, Hung Yy Fau - Sandel ME, Sandel ME. Time to inpatient rehabilitation hospital admission and functional outcomes of stroke patients. (1934-1563 (Electronic)).

204. Russell KL, Holloway Tm Fau - Brum M, Brum M Fau - Caruso V, Caruso V Fau - Chessex C, Chessex C Fau - Grace SL, Grace SL. Cardiac rehabilitation wait times: effect on enrollment. (1932-751X (Electronic)).

205. Graham MM, Knudtson ML, O'Neill BJ, Ross DB, Group CCSAtCW. Treating the right patient at the right time: Access to cardiac catheterization, percutaneous coronary intervention and cardiac surgery. Can J Cardiol. 2006;22(8):679-83.

206. Russell KL, Holloway TM, Brum M, Caruso V, Chessex C, Grace SL. Cardiac rehabilitation wait times: effect on enrollment. J Cardiopulm Rehabil Prev. 2011;31(6):373-7.

207. Stucki G, Stier-Jarmer M, Grill E, Melvin J. Rationale and principles of early rehabilitation care after an acute injury or illness. Disabil Rehabil. 2005;27(7-8):353-9.

208. Karges J, Smallfied S. A description of the outcomes, frequency, duration, and intensity of occupational, physical, and speech therapy in inpatient stroke rehabilitation. J Allied Health. 2009;38(1):E1-10.

209. Mackay LE, Bernstein BA, Chapman PE, Morgan AS, Milazzo LS. Early intervention in severe head injury: long-term benefits of a formalized program. Arch Phys Med Rehabil. 1992;73(7):635-41.

210. Schweickert WD, Pohlman MC, Pohlman AS, Nigos C, Pawlik AJ, Esbrook CL, et al. Early physical and occupational therapy in mechanically ventilated, critically ill patients: a randomised controlled trial. Lancet. 2009;373(9678):1874-82.

211. Brohi K, Cole E, Hoffman K. Improving outcomes in the early phases after major trauma. Curr Opin Crit Care. 2011;17(5):515-9.

212. Dyas J, Ayres P, Airey M, Connelly J. Management of major trauma: changes required for improvement. Qual Health Care. 1999;8(2):78-85.

213. Taheri PA, Iteld LH, Michaels AJ, Edelstein S, Di Ponio L, Rodriguez JL. Physician resource utilization after geriatric trauma. J Trauma. 1997;43(4):565-8; discussion 8-9.

214. Siegler JE, Boehme AK, Fowler BD, George AJ, Monlezun DJ, Albright KC, et al. Inpatient rehabilitation centers and concern for increasing volume of ischemic stroke patients requiring rehabilitation. South Med J. 2013;106(12):693-6.

215. Needham DM, Korupolu R. Rehabilitation quality improvement in an intensive care unit setting: implementation of a quality improvement model. Top Stroke Rehabil. 2010;17(4):271-81.

216. Needham DM, Korupolu R, Zanni JM, Pradhan P, Colantuoni E, Palmer JB, et al. Early physical medicine and rehabilitation for patients with acute respiratory failure: a quality improvement project. Arch Phys Med Rehabil. 2010;91(4):536-42.

217. NHS England. NHS Standard Contract for Major Trauma Service (All ages) London: NHS England, NHS Commissioning Board; 2013 [cited 2014 8th September]. NHS England D15/S/a, Gateway Reference 01365:[Available from: http://www.england.nhs.uk/wp-content/uploads/2014/04/d15-major-trauma-0414.pdf.

218. Department of Health D. Payment by Results Guidance for 2013-14. Leeds: DH; 2014.

219. Palmer C. Major trauma and the injury severity score--where should we set the bar? Annu Proc Assoc Adv Automot Med. 2007;51:13-29.

220. Turner-Stokes L, Sutch S, Dredge R. Healthcare tariffs for specialist inpatient neurorehabilitation services: rationale and development of a UK casemix and costing methodology. Clin Rehabil. 2012;26(3):264-79.

221. Farrar S, Yi D, Sutton M, Chalkley M, Sussex J, Scott A. Has payment by results affected the way that English hospitals provide care? Difference-in-differences analysis. Bmj. 2009;339:b3047.

222. Turner-Stokes L. Politics, policy and payment--facilitators or barriers to person-centred rehabilitation? Disabil Rehabil. 2007;29(20-21):1575-82.

223. Turner-Stokes L, Bill A, Dredge R. A cost analysis of specialist inpatient neurorehabilitation services in the UK. Clin Rehabil. 2012;26(3):256-63.

224. Gillen R, Tennen H, McKee T. The impact of the inpatient rehabilitation facility prospective payment system on stroke program outcomes. Am J Phys Med Rehabil. 2007;86(5):356-63.

225. Rinere O'Brien S. Trends in inpatient rehabilitation stroke outcomes before and after advent of the prospective payment system: a systematic review. J Neurol Phys Ther. 2010;34(1):17-23.

226. Hoffman JM, Donoso Brown E, Chan L, Dikmen S, Temkin N, Bell KR. Change in inpatient rehabilitation admissions for individuals with traumatic brain injury after implementation of the Medicare inpatient rehabilitation facility prospective payment system. Arch Phys Med Rehabil. 2012;93(8):1305-12.

227. Khan F, Pallant JF, Zhang N, Turner-Stokes L. Clinical practice improvement approach in multiple sclerosis rehabilitation: a pilot study. Int J Rehabil Res. 2010;33(3):238-47.

228. Troigros O, Béjot Y, Rodriguez PM, Shoaib F, Ellis H, Wade D. Measuring complexity in neurological rehabilitation: the Oxford Case Complexity Assessment Measure (OCCAM). Clin Rehabil. 2013.

229. de Jonge P, Huyse FJ, Slaets JP, Sollner W, Stiefel FC. Operationalization of biopsychosocial case complexity in general health care: the INTERMED project. Aust N Z J Psychiatry. 2005;39(9):795-9.

230. Latour CH, Huyse FJ, de Vos R, Stalman WA. A method to provide integrated care for complex medically ill patients: the INTERMED. Nurs Health Sci. 2007;9(2):150-7.

231. Wincata J, Weiss M, Marquart B, Alexandrowicz R. Screening instruments for general hospital and primary care patients. Adv Psychosom Med. 2004;26:74-97.

232. Huyse FJ, Lyons JS, Stiefel FC, Slaets JP, de Jonge P, Fink P, et al. "INTERMED": a method to assess health service needs. I. Development and reliability. Gen Hosp Psychiatry. 1999;21(1):39-48.

233. Zorowitz RD. Inpatient rehabilitation facilities under the prospective payment system: lessons learned. Eur J Phys Rehabil Med. 2009;45(2):259-63.

234. Stineman MG, Kallen MA, Thompson C, Gage B. Challenges in paying for effective stays. Med Care. 43. United States2005. p. 841-3.

235. Mahoney FI, Barthel DW. Functional evaluation: The Barthel Index. Maryland State Medical Journal. 1965;14:61-5.

236. Granger CV, Dewis LS, Peters NC, Sherwood CC, Barrett JE. Stroke rehabilitation: analysis of repeated Barthel index measures. Arch Phys Med Rehabil. 1979;60(1):14-7.

237. Green J, Gordon R. The development of Version 2 of the AN-SNAP casemix classification system. Aust Health Rev. 2007;31 Suppl 1:S68-78.

238. Turner-Stokes L, Sutch S, Dredge R, Eagar K. International casemix and funding models: lessons for rehabilitation. Clin Rehabil. 2012;26(3):195-208.

239. Turner-Stokes L, Williams H, Siegert RJ. The Rehabilitation Complexity Scale version 2: a clinimetric evaluation in patients with severe complex neurodisability. J Neurol Neurosurg Psychiatry. 2010;81(2):146-53.

240. Turner-Stokes L, Disler R, Williams H. The Rehabilitation Complexity Scale: a simple, practical tool to identify 'complex specialised' services in neurological rehabilitation. Clin Med. 2007;7(6):593-9.

241. British Society for Rehabilitation Medicine B. Specialist Rehabilitation in the Trauma pathway: BSRM core standards London: BSRM; 2013 [cited 2014 10th July]. Available from: http://www.bsrm.co.uk/Publications/BSRM%20Core%20standards%20for%20Major%20Trauma%2030-5-13.pdf.

242. Hoffman K, West A, Nott P, Cole E, Playford D, Liu C, et al. Measuring acute rehabilitation needs in trauma: preliminary evaluation of the Rehabilitation Complexity Scale. Injury. 2013;44(1):104-9.

243. Stucki G, Grimby G. Applying the ICF in medicine. J Rehabil Med. 2004(44 Suppl):5-6.

244. WHO WHO. International Classification of Functioning, Disability and Health: ICF. Geneva: World Health Organisation, 2001.

245. Dahl TH. International classification of functioning, disability and health: an introduction and discussion of its potential impact on rehabilitation services and research. J Rehabil Med. 2002;34(5):201-4.

246. Engel GL. The need for a new medical model: a challenge for biomedicine. Science. 1977;196(4286):129-36.

247. Institute of Medicine (US) Committee on Disability in America I. The Future of Disability in America. Washington DC: 2007.

248. Whiteneck G, Dijkers MP. Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. Arch Phys Med Rehabil. 90. United States2009. p. S22-35.

249. Eide AH, Jelsma J, Loeb M, Maart S, Toni MK. Exploring ICF components in a survey among Xhosa speakers in Eastern & Western Cape, South Africa. Disabil Rehabil. 30. England2008. p. 819-29.

250. van der Mei SF, Dijkers MP, Heerkens YF. Participation as an outcome measure in psychosocial oncology: content of cancer-specific health-related quality of life instruments. Qual Life Res. 2011;20(10):1617-27.

251. Dijkers MP. Issues in the conceptualization and measurement of participation: an overview. Arch Phys Med Rehabil. 91. United States: 2010 American Congress of Rehabilitation Medicine. Published by Elsevier Inc; 2010. p. S5-16.

252. Noonan VK, Kopec JA, Noreau L, Singer J, Chan A, Mâsse LC, et al. Comparing the content of participation instruments using the international classification of functioning, disability and health. Health Qual Life Outcomes. 2009;7:93.

253. Whiteneck GG. Issues affecting the selection of participation measurement in outcomes research and clinical trials. Arch Phys Med Rehabil. 91. United States: 2010 American Congress of Rehabilitation Medicine. Published by Elsevier Inc; 2010. p. S54-9.

254. Huber JG, Sillick J, Skarakis-Doyle E. Personal perception and personal factors: incorporating health-related quality of life into the International Classification of Functioning, Disability and Health. Disabil Rehabil. 2010;32(23):1955-65.

255. Kostanjsek N, Rubinelli S, Escorpizo R, Cieza A, Kennedy C, Selb M, et al. Assessing the impact of health conditions using the ICF. Disabil Rehabil. 2011;33(15-16):1475-82.

256. Kucukdeveci AA, Tennant A, Grimby G, Franchignoni F. Strategies for assessment and outcome measurement in physical and rehabilitation medicine: an educational review. Journal of Rehabilitation Medicine. 2011;43(8):661-72.

257. Lund ML, Fisher AG, Lexell J, Bernspang B. Impact on participation and autonomy questionnaire: internal scale validity of the Swedish version for use in people with spinal cord injury. J Rehabil Med. 2007;39(2):156-62.

258. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustün BT, Stucki G. Identification of candidate categories of the International Classification of Functioning Disability and Health (ICF) for a Generic ICF Core Set based on regression modelling. BMC Med Res Methodol. 2006;6:36.

259. Bostan C, Oberhauser C, Cieza A. Investigating the dimension functioning from a condition-specific perspective and the qualifier scale of the International Classification of Functioning, Disability, and Health based on Rasch analyses. Am J Phys Med Rehabil. 2012;91(13 Suppl 1):S129-40.

260. Uhlig T, Moe R, Reinsberg S, Kvien TK, Cieza A, Stucki G. Responsiveness of the International Classification of Functioning, Disability and Health (ICF) Core Set for rheumatoid arthritis. Ann Rheum Dis. 2009;68(6):879-84.

261. Grill E, Stucki G. Scales could be developed based on simple clinical ratings of International Classification of Functioning, Disability and Health Core Set categories. J Clin Epidemiol. 2009;62(9):891-8.

262. Grill E, Furman JM, Alghwiri AA, Muller M, Whitney SL. Using core sets of the international classification of functioning, disability and health (ICF) to measure disability in vestibular disorders: study protocol. J Vestib Res. 2013;23(6):297-303.

263. World Health Organisation W. ICF Checklist Version 2.1a, Clinical Form for International Classification of Functioning, Disability and Health: ICF Geneva: WHO; 2001 [cited 2014 13th September]. Available from: http://www.who.int/classifications/icf/training/icfchecklist.pdf.

264. Üstün T, Kostanjsek N, Chatterji S, Rehm J. Measuring Health and Disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0). Geneva: Switzerland: World Health Organization; 2010.

265. Pösl M, Cieza A, Stucki G. Psychometric properties of the WHODASII in rehabilitation patients. Qual Life Res. 2007;16(9):1521-31.

266. Tutelyan VA, Chatterji S, Baturin AK, Pogozheva AV, Kishko ON, Akolzina SE. The Health and Functioning ICF-60: Development and Psychometric Properties. Clin Psychol Psychother. 2014.

267. van Brakel WH, Anderson AM, Mutatkar RK, Bakirtzief Z, Nicholls PG, Raju MS, et al. The Participation Scale: measuring a key concept in public health. Disabil Rehabil. 2006;28(4):193-203.

268. Gandek B, Sinclair SJ, Jette AM, Ware JE, Jr. Development and initial psychometric evaluation of the participation measure for post-acute care (PM-PAC). Am J Phys Med Rehabil. 2007;86(1):57-71.

269. Grill E, Strobl R, Müller M, Quittan M, Kostanjsek N, Stucki G. ICF Core Sets for early post-acute rehabilitation facilities. J Rehabil Med. 2011;43(2):131-8.

270. Soberg HL, Sandvik L, Ostensjo S. Reliability and applicability of the ICF in coding problems, resources and goals of persons with multiple injuries. Disabil Rehabil. 2008;30(2):98-106.

271. Grill E, Mittrach R, Müller M, Mutschler W, Schwarzkopf SR. [Systematic review of measurement instruments and concepts used for functioning outcome in multiple trauma]. Unfallchirurg. 2010;113(6):448-55.

272. Stucki G, Ewert T, Cieza A. Value and application of the ICF in rehabilitation medicine. Disabil Rehabil. 2002;24(17):932-8.

273. Stucki G, Cieza A, Ewert T, Kostanjsek N, Chatterji S, Ustün TB. Application of the nternational Classification of Functioning, Disability and Health (ICF) in clinical practice. Disabil Rehabil. 2002;24(5):281-2.

274. Selb M, Escorpizo R, Kostanjsek N, Stucki G, Ustun B, Cieza A. A guide on how to develop an international classification of functioning, disability and health core set. Eur J Phys Rehabil Med. 2014.

275. Bickenbach JC, Cieza A, Rauch A, Stucki G. ICF Core Sets. Manual for Clinical Practice. Stucki G, editor. Göttingen: Hogrefe; 2012.

276. Grill E, Quittan M, Fialka-Moser V, Müller M, Strobl R, Kostanjsek N, et al. Brief ICF Core Sets for the acute hospital. J Rehabil Med. 2011;43(2):123-30.

277. Cieza A, Ewert T, Ustün TB, Chatterji S, Kostanjsek N, Stucki G. Development of ICF Core Sets for patients with chronic conditions. J Rehabil Med. 2004(44 Suppl):9-11.

278. Stier-Jarmer M, Grill E, Ewert T, Bartholomeyczik S, Finger M, Mokrusch T, et al. ICF Core Set for patients with neurological conditions in early post-acute rehabilitation facilities. Disabil Rehabil. 2005;27(7-8):389-95.

279. Wildner M, Quittan M, Portenier L, Wilke S, Boldt C, Stucki G, et al. ICF Core Set for patients with cardiopulmonary conditions in early post-acute rehabilitation facilities. Disabil Rehabil. 2005;27(7-8):397-404.

280. Coenen M, Cieza A, Freeman J, Khan F, Miller D, Weise A, et al. The development of ICF Core Sets for multiple sclerosis: results of the International Consensus Conference. J Neurol. 2011;258(8):1477-88.

281. Cieza A, Kirchberger I, Biering-Sorensen F, Baumberger M, Charlifue S, Post MW, et al. ICF Core Sets for individuals with spinal cord injury in the long-term context. Spinal Cord. 2010;48(4):305-12.

282. Finger ME, Escorpizo R, Glassel A, Gmunder HP, Luckenkemper M, Chan C, et al. ICF Core Set for vocational rehabilitation: results of an international consensus conference. Disabil Rehabil. 2012;34(5):429-38.

283. Stucki G, Kostanjsek N, Ustün B, Cieza A. ICF-based classification and measurement of functioning. Eur J Phys Rehabil Med. 2008;44(3):315-28.

284. Grill E, Stucki G. Criteria for validating comprehensive ICF Core Sets and developing brief ICF Core Set versions. J Rehabil Med. 2011;43(2):87-91.

285. Kirchberger I, Coenen M, Hierl FX, Dieterle C, Seissler J, Stucki G, et al. Validation of the International Classification of Functioning, Disability and Health (ICF) core set for diabetes mellitus from the patient perspective using focus groups. Diabet Med. 2009;26(7):700-7.

286. Ustun B, Chatterji S, Kostanjsek N. Comments from WHO for the Journal of Rehabilitation Medicine Special Supplement on ICF Core Sets. J Rehabil Med. 2004(44 Suppl):7-8.

287. Geyh S, Kurt T, Brockow T, Cieza A, Ewert T, Omar Z, et al. Identifying the concepts contained in outcome measures of clinical trials on stroke using the International Classification of Functioning, Disability and Health as a reference. J Rehabil Med. 2004(44 Suppl):56-62.

288. Steiner WA, Ryser L, Huber E, Uebelhart D, Aeschlimann A, Stucki G. Use of the ICF model as a clinical problem-solving tool in physical therapy and rehabilitation medicine. Phys Ther. 2002;82(11):1098-107.

289. Stucki G. International Classification of Functioning, Disability, and Health (ICF): a promising framework and classification for rehabilitation medicine. Am J Phys Med Rehabil. 2005;84(10):733-40.

290. Vall J, Costa CM, Pereira LF, Friesen TT. Application of International Classification of Functioning, Disability and Health (ICF) in individuals with spinal cord injury. Arq Neuropsiquiatr. 2011;69(3):513-8.

291. Stier-Jarmer M, Cieza A, Borchers M, Stucki G. How to apply the ICF and ICF core sets for low back pain. Clin J Pain. 2009;25(1):29-38.

292. Grundmann J, Keller K, Brauning-Edelmann M. [The practical application of the International Classification of Functioning, Disability and Health (ICF) in medical rehabilitation of psychiatric patients]. Rehabilitation (Stuttg). 2005;44(6):335-43.

293. Kurtais Y, Oztuna D, Kucukdeveci AA, Kutlay S, Hafiz M, Tennant A. Reliability, construct validity and measurement potential of the ICF comprehensive core set for osteoarthritis. BMC Musculoskelet Disord. 2011;12:255.

294. Oberhauser C, Escorpizo R, Boonen A, Stucki G, Cieza A. Statistical validation of the brief International Classification of Functioning, Disability and Health Core Set for osteoarthritis based on a large international sample of patients with osteoarthritis. Arthritis Care Res (Hoboken). 2013;65(2):177-86.

295. Paanalahti M, Alt Murphy M, Lundgren-Nilsson A, Sunnerhagen KS. Validation of the Comprehensive ICF Core Set for stroke by exploring the patient's perspective on functioning in everyday life: a qualitative study. Int J Rehabil Res. 2014.

296. Glässel A, Kirchberger I, Linseisen E, Stamm T, Cieza A, Stucki G. Content validation of the International Classification of Functioning, Disability and Health (ICF) Core Set for stroke: the perspective of occupational therapists. Can J Occup Ther. 2010;77(5):289-302.

297. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: what is it and why use it? When should it be applied, and what should one look for in a Rasch paper? Arthritis Rheum. 2007;57(8):1358-62.

298. Jette AM, Haley SM. Contemporary measurement techniques for rehabilitation outcomes assessment. J Rehabil Med. 2005;37(6):339-45.

299. Cieza A, Hilfiker R, Chatterji S, Kostanjsek N, Ustun BT, Stucki G. The International Classification of Functioning, Disability, and Health could be used to measure functioning. J Clin Epidemiol. 2009;62(9):899-911.

300. Saketkoo LA, Escorpizo R, Keen KJ, Fligelstone K, Distler O, EUSTAR. International Classification of Functioning, Disability and Health Core Set construction in systemic sclerosis and other rheumatic diseases: a EUSTAR initiative. Rheumatology (Oxford). 2012;51(12):2170-6.

301. Jelsma J. Use of the International Classification of Functioning, Disability and Health: a literature survey. J Rehabil Med. 2009;41(1):1-12.

302. Bryman A. *Social research methods*. 3rd ed. Oxford: University Press. 2008.

303. Creswell J, Plano Clark V, Gutmann M, Hanson W. Advanced mixed methods research designs. In: Tashakkori A, Teddlie C, editors. Handbook of mixed methods in social and behavioural research. Thousand Oaks: CA: Sage; 2003. p. 209-40.

304. Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? BMJ. 2001;322(7294):1115-7.

305. Kroll T, Morris J. Challenges and opportunities in using mixed method designs in rehabilitation research. Arch Phys Med Rehabil. 2009;90(11 Suppl):S11-6.

306. Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. Health Serv Res. 2013;48(6 Pt 2):2134-56.

307. Robson C. Real World Research. West Sussex: UK: John Wiley & Sons Ltd; 2011.

308. Greenhalgh T, Taylor R. Papers that go beyond numbers (qualitative research). Bmj. 1997;315(7110):740-3.

309. Crowther D, Lancaster G. Research Methods: A Concise Introduction to Research in Management and Business Consultancy. Linacre House, Oxford: Elsevier Butterworth-Heinemann; 2008.

310. Ramanathan R. The Role of Organisational Change Management in Offshore Outsourcing of Information Technology Services: Qualitative Case Studies from a Multinational Pharmaceutical Company. Florida: Universal Publishers; 2008.

311. Creswell J. Qualitative Inquiry and Research Design: Choosing among Five Approaches: Sage Publications, Inc; 2006.

312. Jasper MA. Issues in phenomenology for researchers of nursing. J Adv Nurs. 1994;19(2):309-4.

313. Reeves S. Why use theories in qualitative research? BMJ. 2008;337.

314. Jacelon CS, Henneman EA. Dignity in the older critically ill adult: The family member's perspective. Heart Lung. 2014.

315. Mahoney FI,Barthel DW. Funtional evaluation: The Barthel Index. Md State Med J. 1965;14:61-5.

316. Skinner A, Turner-Stokes L. The use of standardized outcome measures in rehabilitation centres in the UK. Clin Rehabil. 2006;20(7):609-15.

317. Salter KL, Teasell RW, Foley NC, Jutai JW. Outcome assessment in randomized controlled trials of stroke rehabilitation. Am J Phys Med Rehabil. 2007;86(12):1007-12.

318. Hobart JC, Lamping DL, Freeman JA, Langdon DW, McLellan DL, Greenwood RJ, et al. Evidence-based measurement: which disability scale for neurologic rehabilitation? Neurology. 2001;57(4):639-44.

319. van der Putten JJ, Hobart JC, Freeman JA, Thompson AJ. Measuring change in disability after inpatient rehabilitation: comparison of the responsiveness of the Barthel index and the Functional Independence Measure. J Neurol Neurosurg Psychiatry. 1999;66(4):480-4.

320. Sangha H, Lipson D, Foley N, Salter K, Bhogal S, Pohani G, et al. A comparison of the Barthel Index and the Functional Independence Measure as outcome measures in stroke rehabilitation: patterns of disability scale usage in clinical trials. Int J Rehabil Res. 2005;28(2):135-9.

321. Hsueh IP, Lin JH, Jeng JS, Hsieh CL. Comparison of the psychometric characteristics of the functional independence measure, 5 item Barthel index, and 10 item Barthel index in patients with stroke. J Neurol Neurosurg Psychiatry. 2002;73(2):188-90.

322. Wallace D, Duncan PW, Lai SM. Comparison of the responsiveness of the Barthel Index and the motor component of the Functional Independence Measure in stroke: the impact of using different methods for measuring responsiveness. J Clin Epidemiol. 2002;55(9):922-8.

323. Schepers VP, Ketelaar M, Visser-Meily JM, Dekker J, Lindeman E. Responsiveness of functional health status measures frequently used in stroke research. Disabil Rehabil. 2006;28(17):1035-40.

324. Granger CV, Hamilton BB, Gresham GE, Kramer AA. The stroke rehabilitation outcome study: Part II. Relative merits of the total Barthel index score and a four-item subscore in predicting patient outcomes. Arch Phys Med Rehabil. 1989;70(2):100-3.

325. Houlden H, Edwards M, McNeil J, Greenwood R. Use of the Barthel Index and the Functional Independence Measure during early inpatient rehabilitation after single incident brain injury. Clin Rehabil. 2006;20(2):153-9.

326. Salter K, Jutai JW, Teasell R, Foley NC, Bitensky J, Bayley M. Issues for selection of outcome measures in stroke rehabilitation: ICF activity. Disabil Rehabil. 2005;27(6):315-40.

327. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. Int Disabil Stud. 1988;10(2):61-3.

328. Sinoff G, Ore L. The Barthel activities of daily living index: self-reporting versus actual performance in the old-old (> or = 75 years). J Am Geriatr Soc. 1997;45(7):832-6.

329. Kwon S, Hartzema AG, Duncan PW, Min-Lai S. Disability measures in stroke: relationship among the Barthel Index, the Functional Independence Measure, and the Modified Rankin Scale. Stroke. 2004;35(4):918-23.

330. Bolorunduro OB, Villegas C, Oyetunji TA, Haut ER, Stevens KA, Chang DC, et al. Validating the Injury Severity Score (ISS) in different populations: ISS predicts mortality better among Hispanics and females. J Surg Res. 2011;166(1):40-4.

331. GraphPad. GraphPad Software Inc. San Diego:CA: GraphPad.

332. Dancey C, Reidy J. *Statistics without Maths for Psychology: using SPSS for Windows*. 3rd ed. Harlow: Essex: Pearson: Prentice Hall; 2004.

333. Carlson MD, Morrison RS. Study design, precision, and validity in observational studies. J alliat Med. 2009;12(1):77-82.

334. Song JW, Chung KC. Observational studies: cohort and case-control studies. Plast Reconstr Surg. 2010;126(6):2234-42.

335. Turner-Stokes L, Scott H, Williams H, Siegert R. The Rehabilitation Complexity Scale--extended version: detection of patients with highly complex needs. Disabil Rehabil. 2012;34(9):715-20.

336. SSNDS. Specialised Rehabilitation Services for Brain Injury and Complex Disability (all ages) - 2014 [cited 2013]. Available from: http://www.yhscg.nhs.uk/SSNDS-Version-3/07%20Specialised%20Rehabilitation%20Services%20etc%20_all%20ages_.pdf.

337. Wade DT, Collin C. The Barthel ADL Index: a standard measure of physical disability? Int Disabil Stud. 1988;10(2):64-7.

338. Quinn TJ, Langhorne P, Stott DJ. Barthel index for stroke trials: development, properties, and application. Stroke. 2011;42(4):1146-51.

339. Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol Group. Ann Med. 2001;33(5):337-43.

340. Janssen MF, Pickard AS, Golicki D, Gudex C, Niewada M, Scalone L, et al. Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study. Qual Life Res. 2013;22(7):1717-27.

341. Wu AW, Jacobson KL, Frick KD, Clark R, Revicki DA, Freedberg KA, et al. Validity and responsiveness of the euroqol as a measure of health-related quality of life in people enrolled in an AIDS clinical trial. Qual Life Res. 2002;11(3):273-82.

342. Pickard AS, Wilke C, Jung E, Patel S, Stavem K, Lee TA. Use of a preference-based measure of health (EQ-5D) in COPD and asthma. Respir Med. 2008;102(4):519-36.

343. Pickard AS, Wilke CT, Lin HW, Lloyd A. Health utilities using the EQ-5D in studies of cancer. Pharmacoeconomics. 2007;25(5):365-84.

344. Huang IC, Willke RJ, Atkinson MJ, Lenderking WR, Frangakis C, Wu AW. US and UK versions of the EQ-5D preference weights: does choice of preference weights make a difference? Qual Life Res. 2007;16(6):1065-72.

345. Dyer MT, Goldsmith KA, Sharples LS, Buxton MJ. A review of health utilities using the EQ-5D in studies of cardiovascular disease. Health Qual Life Outcomes. 2010;8:13.

346. Black JA, Herbison GP, Lyons RA, Polinder S, Derrett S. Recovery after injury: an individual patient data meta-analysis of general health status using the EQ-5D. J Trauma. 2011;71(4):1003-10.

347. Polinder S, Haagsma JA, Belt E, Lyons RA, Erasmus V, Lund J, et al. A systematic review of studies measuring health-related quality of life of general injury populations. BMC Public Health. 2010;10:783.

348. Vos T, Flaxman AD, Naghavi M, Lozano R, Michaud C, Ezzati M, et al. Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380(9859):2163-96.

349. Dolan P. Modeling valuations for EuroQol health states. Med Care. 1997;35(11):1095-108.

350. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, et al. Linking health-status measurements to the international classification of functioning, disability and health. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine. 2002;34(5):205-10.

351. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustün B, Stucki G. ICF linking rules: an update based on lessons learned. J Rehabil Med. 2005;37(4):212-8.

352. World Health Organisation W. World Health Organisation, International Classification of Function, Disability and Health. Geneva: WHO; 2001.

353. Moher D, Liberati A, Tetzlaff J, Altman DG, Group P. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med. 2009;6(7):e1000097.

354. Guyatt GH, Oxman AD, Vist G, Kunz R, Brozek J, Alonso-Coello P, et al. GRADE guidelines: 4. Rating the quality of evidence--study limitations (risk of bias). J Clin Epidemiol. 2011;64(4):407-15.

355. Guyatt GH, Oxman AD, Vist GE, Kunz R, Falck-Ytter Y, Alonso-Coello P, et al. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. BMJ. 2008;336(7650):924-6.

356. Guyatt GH, Oxman AD, Kunz R, Vist GE, Falck-Ytter Y, Schünemann HJ, et al. What is "quality of evidence" and why is it important to clinicians? BMJ. 2008;336(7651):995-8.

357. BMJ BMJ. Grading quality of evidence and strength of recommendations. British Medical Journal. 2004;328:1490.

358. Geyh S, Cieza A, Kollerits B, Grimby G, Stucki G. Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): a systematic review. Qual Life Res. 2007;16(5):833-51.

359. Velstra IM, Ballert CS, Cieza A. A systematic literature review of outcome measures for upper extremity function using the international classification of functioning, disability, and health as reference. PM R. 2011;3(9):846-60.

360. Gradinger F, Glässel A, Bentley A, Stucki A. Content comparison of 115 health status measures in sleep medicine using the International Classification of Functioning, Disability and Health (ICF) as a reference. Sleep Med Rev. 2011;15(1):33-40.

361. Grill E, Quittan M, Huber EO, Boldt C, Stucki G. Identification of relevant ICF categories by health professionals in the acute hospital. Disabil Rehabil. 2005;27(7-8):437-45.

362. Grill E, Ewert T, Chatterji S, Kostanjsek N, Stucki G. ICF Core Sets development for the acute hospital and early post-acute rehabilitation facilities. Disabil Rehabil. 2005;27(7-8):361-6.

363. Müller M, Stier-Jarmer M, Quittan M, Strobl R, Stucki G, Grill E. Validation of the comprehensive ICF Core Sets for patients in early post-acute rehabilitation facilities. J Rehabil Med. 2011;43(2):102-12.

364. Müller M, Grill E, Stier-Jarmer M, Strobl R, Gutenbrunner C, Fialka-Moser V, et al. Validation of the comprehensive ICF Core Sets for patients receiving rehabilitation interventions in the acute care setting. J Rehabil Med. 2011;43(2):92-101.

365. Grill E, Stucki G, Scheuringer M, Melvin J. Validation of International Classification of Functioning, Disability, and Health (ICF) Core Sets for early postacute rehabilitation facilities: comparisons with three other functional measures. Am J Phys Med Rehabil. 2006;85(8):640-9.

366. SurveyMonkey. SurveyMonkey ® online web platform Palo Alto, California, USA: SurveyMonkey Inc. Available from: www.surveymonkey.com.

367. Boonen A, van Berkel M, Kirchberger I, Cieza A, Stucki G, van der Heijde D. Aspects relevant for functioning in patients with ankylosing spondylitis according to the health professionals: a Delphi study with the ICF as reference. Rheumatology (Oxford). 2009;48(8):997-1002.

368. Lemberg I, Kirchberger I, Stucki G, Cieza A. The ICF Core Set for stroke from the perspective of physicians: a worldwide validation study using the Delphi technique. Eur J Phys Rehabil Med. 2010;46(3):377-88.

369. Weigl M, Cieza A, Andersen C, Kollerits B, Amann E, Stucki G. Identification of relevant ICF categories in patients with chronic health conditions: a Delphi exercise. J Rehabil Med. 2004(44 Suppl):12-21.

370. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, et al. Linking health-status measurements to the International Classification of Functioning, Disability and Health. J Rehabil Med. 2002;34:1-6.

371. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B, Stucki G. ICF linking rules: an update based on lessons learned. J Rehabil Med. 2005;37(4):212-8.

372. Bowling A, Ebrahim S. *Handbook of health research methods*. Buckingham: Open University Press; 2005.

373. Gill P, Stewart K, Treasure E, Chadwick B. Methods of data collection in qualitative research: interviews and focus groups. Br Dent J. 2008;204(6):291-5.

374. Donalek JG. The interview in qualitative research. Urol Nurs. 2005;25(2):124-5.

375. Finlay L. Reflexivity: an Essential Component for All Research? The British Journal of Occupational Therapy. 1998;61(10):453-6.

376. Dicicco-Bloom B, Crabtree BF. The qualitative research interview. Med Educ. 2006;40(4):314-21.

377. Clarke A. Qualitative interviewing: encountering ethical issues and challenges. Nurse Res. 2006;13(4):19-29.

378. Nunkoosing K. The problems with interviews. Qual Health Res. 2005;15(5):698-706.

379. Durham R, Pracht E, Orban B, Lottenburg L, Tepas J, Flint L. Evaluation of a mature trauma system. Ann Surg. 2006;243(6):775-83; discussion 83-5.

380. Zagorac S, Bumbasirevic M, Lesic A, Milosevic I. [Epidemiological analysis of demographic characteristics and type of injuries in patients with multiple trauma with respect to conclusive treatment outcome]. Srp Arh Celok Lek. 2008;136(3-4):136-40.

381. Curtis S, Gesler W, Smith G, Washburn S. Approaches to sampling and case selection in qualitative research: examples in the geography of health. Soc Sci Med. 2000;50(7-8):1001-14.

382. Coyne IT. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? Journal of Advanced Nursing. 1997;26(3):623-30.

383. Ringburg AN, Polinder S, van MCM, Steyerberg EW, van EME, Patka P, et al. Prevalence and prognostic factors of disability after major trauma. Journal of Trauma. 2011;70(4):916-23.

384. Gabbe BJ, Cameron PA. Importance of functional and quality of life outcomes in trauma. Surgeon. 2013;11(2):114.

385. Langley J, Derrett S, Davie G, Ameratunga S, Wyeth E. A cohort study of short-term functional outcomes following injury: the role of pre-injury socio-demographic and health characteristics, injury and injury-related healthcare. Health & Quality of Life Outcomes. 2011;9.

386. Sayer NA, Friedemann-Sanchez G, Spoont M, Murdoch M, Parker LE, Chiros C, et al. A qualitative study of determinants of PTSD treatment initiation in veterans. Psychiatry. 2009;72(3):238-55.

387. Sayer NA, Chiros CE, Sigford B, Scott S, Clothier B, Pickett T, et al. Characteristics and rehabilitation outcomes among patients with blast and other injuries sustained during the Global War on Terror. Archives of Physical Medicine & Rehabilitation. 2008;89(1):163-71.

388. Warren C. Qualitative Interviewing. In: Gubrium J, Holstein Je, editors. Handbook of Interview Research: Context and Method. Thousand Oaks, CA: Sage; 2002.

389. Mason M. Sample Size and Saturation in PhD Studies Using Qualitative Interviews [Single Contributions]. Forum Qualitative Sozialforschung/Forum: Qualitative Social Research; 2010 [updated 2010-08-24; cited 2014 18th August]. 11/3,art. 8:[Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 11/3, art. 8]. Available from: http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027.

390. Baldry Currens JA. Evaluation of disability and handicap following injury. Injury. 2000;31(2):99-106.

391. Zelle BA, Bhandari M, Sanchez AI, Probst C, Pape HC. Loss of follow-up in orthopaedic trauma: is 80% follow-up still acceptable? J Orthop Trauma. 2013;27(3):177-81.

392. Langley J, Johnson S, Slatyer M, Skilbeck CE, Thomas M. Issues of loss to follow-up in a population study of traumatic brain injury (TBI) followed to 3 years post-trauma. Brain Inj. 2010;24(7-8):939-47.

393. Malterud K. Systematic text condensation: a strategy for qualitative analysis. Scand J Public Health. 2012;40(8):795-805.

394. Kwale **S**. *Interviews - An Introduction to Qualitative Research Interviewing*. Thousand Oaks, California: Sage Publications; 1996.

395. Mueller M, Lohmann S, Strobl R, Boldt C, Grill E. Patients' functioning as predictor of nursing workload in acute hospital units providing rehabilitation care: a multi-centre cohort study. BMC Health Serv Res. 2010;10:295.
396. Sveen U, Ostensjo S, Laxe S, Soberg HL. Problems in functioning after a mild traumatic brain injury within the ICF framework: the patient perspective using focus groups. Disabil Rehabil. 2013;35(9):749-57.
397. Mays N, Pope C. Rigour and qualitative research. BMJ. 1995;311:109-12.
398. Sumsion T. The Delphi Technique: An Adaptive Research Tool. The British Journal of Occupational Therapy. 1998;61(4):153-6.
399. Sveen U, Ostensjo S, Laxe S, Soberg HL. Problems in functioning after a mild traumatic brain injury within the ICF framework: the patient perspective using focus groups. Disabil Rehabil. 2012.
400. Barker M, Power C, Roberts I. Injuries and the risk of disability in teenagers and young adults. Arch Dis Child. 1996;75(2):156-8.
401. Barker M, Power C. Disability in young adults: the role of injuries. J Epidemiol Community Health. 1993;47(5):349-54.
402. Khan F, Baguley IJ, Cameron ID. 4: Rehabilitation after traumatic brain injury. Med J Aust. 2003;178(6):290-5.
403. Greenwood RJ, Strens LH, Watkin J, Losseff N, Brown MM. A study of acute rehabilitation after head injury. Br J Neurosurg. 2004;18(5):462-6.
404. Wynia MK. The risks of rewards in health care: how pay-for-performance could threaten, or bolster, medical professionalism. J Gen Intern Med. 2009;24(7):884-7.
405. Heinemann AW, Linacre JM, Wright BD, Hamilton BB, Granger C. Prediction of rehabilitation outcomes with disability measures. Arch Phys Med Rehabil. 1994;75(2):133-43.
406. Jette DU, Warren RL, Wirtalla C. Rehabilitation in skilled nursing facilities: effect of nursing staff level and therapy intensity on outcomes. Am J Phys Med Rehabil. 2004;83(9):704-12.
407. Eichhorn-Kissel J, Dassen T, Kottner J, Lohrmann C. Psychometric testing of the modified Care Dependency Scale for Rehabilitation. Clin Rehabil. 2010;24(4):363-72.
408. Leistner K, Stier-Jarmer M, Berleth B, Braun J, Koenig E, Liman W, et al. [Early rehabilitation care in the hospital--definition and indication. Results of the expert group "Early Rehabilitation Care in the Hospital"]. Rehabilitation (Stuttg). 2005;44(3):165-75.
409. Shah S, Vanclay F, Cooper B. Predicting discharge status at commencement of stroke rehabilitation. Stroke. 1989;20(6):766-9.

410. Kosar S, Seelen HA, Hemmen B, Evers SM, Brink PR. Cost-effectiveness of an integrated 'fast track' rehabilitation service for multi-trauma patients involving dedicated early rehabilitation intervention programs: design of a prospective, multi-centre, non-randomised clinical trial. J Trauma Manag Outcomes. 2009;3:1.

411. Stucki G, Ustün TB, Melvin J. Applying the ICF for the acute hospital and early post-acute rehabilitation facilities. Disabil Rehabil. 2005;27(7-8):349-52.

412. Turner-Stokes L, Shaw A, Law J, Rose H. Development and initial validation of the Northwick Park Therapy Dependency Assessment. Clin Rehabil. 2009;23(10):922-37.

413. Scholtes VA, Terwee CB, Poolman RW. What makes a measurement instrument valid and reliable? Injury. 2011;42(3):236-40.

414. Hutchings L, Fox R, Chesser T. Proximal femoral fractures in the elderly: How are we measuring outcome? Injury. 2011;42(11):1205-13.

415. Neugebauer E, Bouillon B, Bullinger M, Wood-Dauphinée S. Quality of life after multiple trauma--summary and recommendations of the consensus conference. Restor Neurol Neurosci. 2002;20(3-4):161-7.

416. Hutchings A, Neuburger J, van der Meulen J, Black N. Estimating recruitment rates for routine use of patient reported outcome measures and the impact on provider comparisons. BMC Health Serv Res. 2014;14:66.

417. Varagunam M, Hutchings A, Neuburger J, Black N. Impact on hospital performance of introducing routine patient reported outcome measures in surgery. J Health Serv Res Policy. 2014;19(2):77-84.

418. Browne JP, Bastaki H, Dawson J. What is the optimal time point to assess patient-reported recovery after hip and knee replacement? A systematic review and analysis of routinely reported outcome data from the English patient-reported outcome measures programme. Health Qual Life Outcomes. 2013;11:128.

419. Hoffman K, West A, Nott P, Cole E, Playford D, Liu C, et al. Measuring acute rehabilitation needs in trauma: Preliminary evaluation of the Rehabilitation Complexity Scale. Injury. 2011.

420. Turner-Stokes L. Evidence for the effectiveness of multi-disciplinary rehabilitation following acquired brain injury: a synthesis of two systematic approaches. J Rehabil Med. 2008;40(9):691-701.

421. Jette DU, Warren RL, Wirtalla C. The relation between therapy intensity and outcomes of rehabilitation in skilled nursing facilities. Arch Phys Med Rehabil. 2005;86(3):373-9.

422. Bradley LJ, Kirker SG, Corteen E, Seeley HM, Pickard JD, Hutchinson PJ. Inappropriate acute neurosurgical bed occupancy and short falls in rehabilitation: implications for the National Service Framework. Br J Neurosurg. 2006;20(1):36-9.

423. Williams H, Harris R, Turner-Stokes L. Work sampling: a quantitative analysis of nursing activity in a neuro-rehabilitation setting. J Adv Nurs. 2009;65(10):2097-107.

424. Meyer T, Gutenbrunner C, Bickenbach J, Cieza A, Melvin J, Stucki G. Towards a conceptual description of rehabilitation as a health strategy. J Rehabil Med. 2011;43(9):765-9.

425. Stucki G, Stier-Jarmer M, Grill E, Melvin J. Rationale and principles of early rehabilitation care after an acute injury or illness. Disabil Rehabil. 2005;27(7-8):353-9.

426. Halcomb E, Davidson P. Using the illness trajectory framework to describe recovery from traumatic injury. Contemp Nurse. 2005;19(1-2):232-41.

427. Langley J, Derrett S, Davie G, Ameratunga S, Wyeth E. A cohort study of short-term functional outcomes following injury: the role of pre-injury socio-demographic and health characteristics, injury and injury-related healthcare. Health Qual Life Outcomes. 2011;9:68.

428. team DoHPbR. Payment by Results Guidance for 2013-14. In: Health Do, editor. Leeds: Department of Health; 2013.

429. Gabbe BJ, Cameron PA, Wolfe R, Simpson P, Smith KL, McNeil JJ. Predictors of mortality, length of stay and discharge destination in blunt trauma. ANZ J Surg. 2005;75(8):650-6.

430. Petryshen P, Pallas LL, Shamian J. Outcomes monitoring: adjusting for risk factors, severity of illness, and complexity of care. J Am Med Inform Assoc. 1995;2(4):243-9.

431. Plsek PE, Greenhalgh T. Complexity science: The challenge of complexity in health care. BMJ. 2001;323(7313):625-8.

432. Polinder S, van Beeck EF, Essink-Bot ML, Toet H, Looman CW, Mulder S, et al. Functional outcome at 2.5, 5, 9, and 24 months after injury in the Netherlands. J Trauma. 2007;62(1):133-41.

433. Pape HC, Probst C, Lohse R, Zelle BA, Panzica M, Stalp M, et al. Predictors of late clinical outcome following orthopedic injuries after multiple trauma. Journal of Trauma. 2010;69(5):1243-52.

434. Orwelius L, Bergkvist M, Nordlund A, Simonsson E, Nordlund P, Bäckman C, et al. Physical Effects of the Trauma and Psychological Consequences of Preexisting Diseases Account for a Significant Portion of the Health-Related Quality of Life Pattern of Former Trauma Patients. J Trauma. 2011.

435. Gabbe BJ, Simpson PM, Sutherland AM, Wolfe R, Fitzgerald MC, Judson R, et al. Improved unctional outcomes for major trauma patients in a regionalized, inclusive trauma system. Ann Surg. 2012;255(6):1009-15.

436. Bowling A. Just one question: If one question works, why ask several? J Epidemiol Community Health. 59. England2005. p. 342-5.

437. Soberg HL, Finset A, Roise O, Bautz-Holter E. The trajectory of physical and mental health from injury to 5 years after multiple trauma: a prospective, longitudinal cohort study. Arch Phys Med Rehabil. 2012;93(5):765-74.

438. Jackson JC, Obremskey W, Bauer R, Greevy R, Cotton BA, Anderson V, et al. Long-term cognitive, emotional, and functional outcomes in trauma intensive care unit survivors without intracranial hemorrhage. J Trauma. 2007;62(1):80-8.

439. Sutherland AG, Alexander DA, Hutchison JD. The mind does matter: Psychological and physical recovery after musculoskeletal trauma. Journal of Trauma. 2006;61(6):1408-15.

440. Sutherland AG, Suttie S, Alexander DA, Hutchison JD. The mind continues to matter: psychologic and physical recovery 5 years after musculoskeletal trauma. Journal of Orthopaedic Trauma. 2011;25(4):228-33.

441. Pirente N, Blum C, Wortberg S, Bostanci S, Berger E, Lefering R, et al. Quality of life after multiple trauma: The effect of early onset psychotherapy on quality of life in trauma patients. Langenbeck's Archives of Surgery. 2007;392(6):739-45.

442. Franzén C, Brulin C, Stenlund H, Björnstig U. Injured road users' health-related quality of life after telephone intervention: a randomised controlled trial. Journal of Clinical Nursing. 2009;18(1):108-17.

443. Steel J, Youssef M, Pfeifer R, Ramirez JM, Probst C, Sellei R, et al. Health-related quality of life in patients with multiple injuries and traumatic brain injury 10+ years postinjury. Journal of Trauma. 2010;69(3):523-32.

444. Jackson JC, Obremskey W, Bauer R, Greevy R, Cotton BA, Anderson V, et al. Long-term cognitive, emotional, and functional outcomes in trauma intensive care unit survivors without intracranial hemorrhage. Journal of Trauma. 2007;62(1):80-9.

445. Kiely JM, Brasel KJ, Weidner KL, Guse CE, Weigelt JA. Predicting quality of life six months after traumatic injury. Journal of Trauma. 2006;61(4):791-9.

446. Livingston DH, Tripp T, Biggs C, Lavery RF. A fate worse than death? Long-term outcome of trauma patients admitted to the surgical intensive care unit. Journal of Trauma. 2009;67(2):341-9.

447. Mackenzie EJ, Rivara FP, Jurkovich GJ, Nathens AB, Egleston BL, Salkever DS, et al. The impact of trauma-center care on functional outcomes following major lower-limb trauma. Journal of Bone & Joint Surgery, American Volume. 2008;90A(1):101-10.

448. Gabbe BJ, Cameron PA, Hannaford AP, Sutherland AM, McNeil JJ. Routine follow up of major trauma patients from trauma registries: What are the outcomes? J Trauma. 2006;61(6):1393-9.

449. Derrett S, Davie G, Ameratunga S, Langley J. Capturing outcomes following injury: a New Zealand pilot study. N Z Med J. 2010;123(1316):66-74.

450. Probst C, Zelle B, Panzica M, Lohse R, Sitarro NA, Krettek C, et al. Clinical re-examination 10 or more years after polytrauma: is there a gender related difference? Journal of Trauma. 2010;68(3):706-12.

451. Zeckey C, Hildebrand F, Pape H-C, Mommsen P, Panzica M, Zelle A, et al. Head injury in polytrauma--Is there an effect on outcome more than 10 years after the injury?? Brain Injury. 2011;25(6):551-60.

452. Baranyi A, Leithgob O, Kreiner B, Tanzer K, Ehrlich G, Hofer HP, et al. Relationship between posttraumatic stress disorder, quality of life, social support, and affective and dissociative status in severely injured accident victims 12 months after trauma. Psychosomatics. 2010;51(3):237-47.

453. Soberg HL, Finset A, Bautz-Holter E, Sandvik L, Roise O. Return to work after severe multiple injuries: a multidimensional approach on status 1 and 2 years postinjury. J Trauma. 2007;62(2):471-81.

454. Orwelius L, Bergkvist M, Nordlund A, Simonsson E, Nordlund P, Bäckman C, et al. Physical effects of trauma and the psychological consequences of preexisting diseases account for a significant portion of the health-related quality of life patterns of former trauma patients. J Trauma Acute Care Surg. 2012;72(2):504-12.

455. Ballabeni P, Burrus C, Luthi F, Gobelet C, Dériaz O. The effect of recalled previous work environment on return to work after a rehabilitation program including vocational aspects for trauma patients. J Occup Rehabil. 2011;21(1):43-53.

456. van Aswegen H, Myezwa H, Mudzi W, Becker P. Health-related quality of life of survivors of penetrating trunk trauma in Johannesburg, South Africa. European Journal of Trauma and Emergency Surgery. 2011;37(4):419-26.

457. Zelle B, Stalp M, Weihs Ch, Muller F, Reiter FO, Krettek Ch, et al. Hannover Score for Polytrauma Outcome (HASPOC). Validierung am Beispiel von 170 Polytrauma-Patienten und Vergleich mit dem SF-12. [Validation of the Hannover Score for Polytrauma Outcome

(HASPOC) in a sample of 170 polytrauma patients and a comparison with the 12-Item Short-Form Health Survey]. Chirurg. 2003;74(4):361-9.

458. Attenberger C, Amsler F, Gross T. Clinical evaluation of the Trauma Outcome Profile (TOP) in the longer-term follow-up of polytrauma patients. Injury. 43. Netherlands: 2011 Elsevier Ltd; 2012. p. 1566-74.

459. Pirente N, Ottlik Y, Lefering R, Boullion B, Neugebauer E. Quality of life in multiply injured patients. European Journal of Trauma. 2006;32(1):44-63.

460. Cieza A, Oberhauser C, Bickenbach J, Chatterji S, Stucki G. Towards a minimal generic set of domains of functioning and health. BMC Public Health. 2014;14(1):218.

461. Polinder S, Meerding WJ, Lyons RA, Haagsma JA, Toet H, Petridou ET, et al. International variation in clinical injury incidence: exploring the performance of indicators based on health care, anatomical and outcome criteria. Accid Anal Prev. 2008;40(1):182-91.

462. Valent F, Little DA, Bertollini R, Nemer LE, Barbone F, Tamburlini G. Burden of disease attributable to selected environmental factors and injury among children and adolescents in Europe. The Lancet. 2004;363(9426):2032-9.

463. Resnik LJ, Allen SM. Using International Classification of Functioning, Disability and Health to understand challenges in community reintegration of injured veterans. Journal of Rehabilitation Research & Development. 2007;44(7):991-1006.

464. Khan F, Pallant JF. Use of the International Classification of Functioning, Disability and Health (ICF) to identify preliminary comprehensive and brief core sets for multiple sclerosis. Disabil Rehabil. 2007;29(3):205-13.

465. Geyh S, Cieza A, Schouten J, Dickson H, Frommelt P, Omar Z, et al. ICF Core Sets for stroke. J Rehabil Med. 2004(44 Suppl):135-41.

466. Copes WS, Champion HR, Sacco WJ, Lawnick MM, Gann DS, Gennarelli T, et al. Progress in characterizing anatomic injury. J Trauma. 1990;30(10):1200-7.

467. Bernd T, Van Der Pijl D, De Witte LP. Existing models and instruments for the selection of assistive technology in rehabilitation practice. Scand J Occup Ther. 2009;16(3):146-58.

468. McGlynn M, Solway S, Lowe M, Howe JA, Hebert D, Velji K. Organizational model and process for clinical best practice in rehabilitation and complex continuing care. Healthc Q. 2011;14(1):62-9.

469. Willis CD, Gabbe BJ, Jolley D, Harrison JE, Cameron PA. Predicting trauma patient mortality: ICD [or ICD-10-AM] versus AIS based approaches. ANZ J Surg. 2010;80(11):802-6.

470. Mueller M, Boldt C, Grill E, Strobl R, Stucki G. Identification of ICF categories relevant for nursing in the situation of acute and early post-acute rehabilitation. BMC Nurs. 2008;7:3.

471. Gabbe BJ, Sleney JS, Gosling CM, Wilson K, Hart MJ, Sutherland AM, et al. Patient perspectives of care in a regionalised trauma system: lessons from the Victorian State Trauma System. Med J Aust. 2013;198(3):149-52.

472. Jelles F, van Bennekom C, Lankhorst G. Instruments to structure interdisciplinary team conferences in rehabilitation medicine: added value of the rehabilitation activities profile. *Journal of Rehabilitation Sciences*. 1995;8(2):51-7.

473. Laxe S, Zasler N, Robles V, López-Blázquez R, Tormos JM, Bernabeu M. ICF profiling of patients with traumatic brain injury: an international professional survey. Disabil Rehabil. 2013.

474. Kirchberger I, Cieza A, Biering-Sørensen F, Baumberger M, Charlifue S, Post MW, et al. ICF Core Sets for individuals with spinal cord injury in the early post-acute context. Spinal Cord. 2010;48(4):297-304.

475. Müller M, Strobl R, Grill E. Goals of patients with rehabilitation needs in acute hospitals: goal achivement is an indicator for improved functioning. J Rehabil Med. 2011;43(2):145-50.

476. Grill E, Lipp B, Boldt C, Stucki G, Koenig E. Identification of relevant ICF categories by patients with neurological conditions in early post-acute rehabilitation facilities. Disabil Rehabil. 2005;27(7-8):459-65.

477. O'Donnell ML, Creamer M, Elliott P, Atkin C, Kossmann T. Determinants of quality of life and role-related disability after injury: impact of acute psychological responses. J Trauma. 2005;59(6):1328-34; discussion 34-5.

478. Holbrook TL, Anderson JP, Sieber WJ, Browner D, Hoyt DB. Outcome after major trauma: 12-month and 18-month follow-up results from the Trauma Recovery Project. J Trauma. 1999;46(5):765-71; discussion 71-3.

479. Richmond TS, Kauder D, Hinkle J, Shults J. Early predictors of long-term disability after injury. Am J Crit Care. 2003;12(3):197-205.

480. Holbrook TL, Hoyt DB, Coimbra R, Potenza B, Sise M, Anderson JP. High rates of acute stress disorder impact quality-of-life outcomes in injured adolescents: mechanism and gender predict acute stress disorder risk. J Trauma. 2005;59(5):1126-30.

481. Gold JI, Kant AJ, Kim SH. The impact of unintentional pediatric trauma: a review of pain, acute stress, and posttraumatic stress. J Pediatr Nurs. 2008;23(2):81-91.

482. Schnyder U, Wittmann L, Friedrich-Perez J, Hepp U, Moergeli H. Posttraumatic stress disorder following accidental injury: rule or exception in Switzerland? Psychother Psychosom. 2008;77(2):111-8.

483. Fuglsang AK, Moergeli H, Schnyder U. Does acute stress disorder predict post-traumatic stress disorder in traffic accident victims? Analysis of a self-report inventory. Nord J Psychiatry. 2004;58(3):223-9.

484. Salah Eldin W, Hirshon JM, Smith GS, Kamal AA, Abou-El-Fetouh A, El-Setouhy M. Health-related quality of life after serious occupational injury in Egyptian workers: a cross-sectional study. BMJ Open. 2012;2(6).

485. Ulvik A, Kvale R, Wentzel-Larsen T, Flaatten H. Quality of life 2-7 years after major trauma. Acta Anaesthesiol Scand. 2008;52(2):195-201.

486. Stulemeijer M, Vos PE, Bleijenberg G, van der Werf SP. Cognitive complaints after mild traumatic brain injury: things are not always what they seem. J Psychosom Res. 2007;63(6):637-45.

487. Stulemeijer M, Andriessen TM, Brauer JM, Vos PE, Van Der Werf S. Cognitive performance after mild traumatic brain injury: the impact of poor effort on test results and its relation to distress, personality and litigation. Brain Inj. 2007;21(3):309-18.

488. Emilien G, Waltregny A. Traumatic brain injury, cognitive and emotional dysfunction. Impact of clinical neuropsychology research. Acta Neurol Belg. 1996;96(2):89-101.

489. Salmond CH, Sahakian BJ. Cognitive outcome in traumatic brain injury survivors. Curr Opin Crit Care. 2005;11(2):111-6.

490. McDonald BC, Flashman LA, Saykin AJ. Executive dysfunction following traumatic brain injury: neural substrates and treatment strategies. NeuroRehabilitation. 2002;17(4):333-44.

491. Finset A, Anke AW, Hofft E, Roaldsen KS, Pillgram-Larsen J, Stanghelle JK. Cognitive performance in multiple trauma patients 3 years after injury. Psychosom Med. 1999;61(4):576-83.

492. Parker RS. The spectrum of emotional distress and personality changes after minor head injury incurred in a motor vehicle accident. Brain Inj. 1996;10(4):287-302.

493. Lin BC, Fang JF, Chen RJ, Wong YC, Hsu YP. Surgical management and outcome of blunt major liver injuries: experience of damage control laparotomy with perihepatic packing in one trauma centre. Injury. 2014;45(1):122-7.

494. Groven S, Gaarder C, Eken T, Skaga NO, Naess PA. Abdominal injuries in a major Scandinavian trauma center - performance assessment over an 8 year period. J Trauma Manag Outcomes. 2014;8:9.

495. Badger SA, Barclay R, Campbell P, Mole DJ, Diamond T. Management of liver trauma. World J Surg. 2009;33(12):2522-37.

496. Bradley M, Galvagno S, Dhanda A, Rodriguez C, Lauerman M, DuBose J, et al. Damage control resuscitation protocol and the management of open abdomens in trauma patients. Am Surg. 2014;80(8):768-75.

497. Dowrick AS, Gabbe BJ, Williamson OD, Wolfe R, Cameron PA. A comparison of self-reported and independently observed disability in an orthopedic trauma population. J Trauma. 2006;61(6):1447-52.

498. Urquhart DM, Williamson OD, Gabbe BJ, Cicuttini FM, Cameron PA, Richardson MD, et al. Outcomes of patients with orthopaedic trauma admitted to level 1 trauma centres. ANZ J Surg. 2006;76(7):600-6.

499. O'Toole RV, Castillo RC, Pollak AN, MacKenzie EJ, Bosse MJ, Group LS. Determinants of patient satisfaction after severe lower-extremity injuries. J Bone Joint Surg Am. 2008;90(6):1206-11.

500. Castillo RC, MacKenzie EJ, Archer KR, Bosse MJ, Webb LX. Evidence of beneficial effect of physical therapy after lower-extremity trauma. Archives of Physical Medicine & Rehabilitation. 2008;89(10):1873-80.

501. Dowrick AS, Gabbe BJ, Williamson OD. Does the presence of an upper extremity injury affect outcomes after major trauma? J Trauma. 2005;58(6):1175-8.

502. Dowrick AS, Gabbe BJ, Williamson OD, Cameron PA. Outcome instruments for the assessment of the upper extremity following trauma: a review. Injury. 2005;36(4):468-76.

503. Bowling A. Measuring health - a review of quality of life scales. Third ed. Berkshire, England: Open University Press; 2005. 211 p.

504. Akmal M, Trivedi R, Sutcliffe J. Functional outcome in trauma patients with spinal injury. Spine. 2003;28(2):180-5.

505. Gabbe BJ, Sutherland AM, Wolfe R, Williamson OD, Cameron PA. Can the modified functional independence measure be reliably obtained from the patient medical record by different raters? J Trauma. 2007;63(6):1374-9.

506. Kohler F, Dickson H, Redmond H, Estell J, Connolly C. Agreement of functional independence measure item scores in patients transferred from one rehabilitation setting to another. Eur J Phys Rehabil Med. 2009;45(4):479-85.

507. Griffin JM, Friedemann-Sánchez G, Hall C, Phelan S, van M. Families of patients with polytrauma: understanding the evidence and charting a new research agenda. Research to Improve the Lives of Veterans: Approaches to Traumatic Brain Injury; Screening, Treatment, Management, and Rehabilitation in Arlington, Virginia, April 30 to May 2, 2008. Journal of Rehabilitation Research & Development. 2009;46(6):879-92.

508. Griffin JM, Friedemann-Sánchez G, Jensen AC, Taylor BC, Gravely A, Clothier B, et al. The invisible side of war: families caring for US service members with traumatic brain injuries and polytrauma. J Head Trauma Rehabil. 2012;27(1):3-13.

509. Khan F, Pallant JF. Use of International Classification of Functioning, Disability and Health (ICF) to describe patient-reported disability in multiple sclerosis and identification of relevant environmental factors. J Rehabil Med. 2007;39(1):63-70.

510. Hoefsmit N, Houkes I, Nijhuis F. Environmental and personal factors that support early return-to-work: a qualitative study using the ICF as a framework. Work. 2014;48(2):203-15.

511. Riberto M, Chiappetta LM, Lopes KA, Chiappetta LR. A transversal multicenter study assessing functioning, disability and environmental factors with the comprehensive ICF core set for low back pain in Brazil. Eur J Phys Rehabil Med. 2014;50(2):153-60.

512. Greatorex J, Dexter T. An accessible analytical approach for investigating what happens between the rounds of a Delphi study. J Adv Nurs. 2000;32(4):1016-24.

513. Keeney S, Hasson F, McKenna HP. A critical review of the Delphi technique as a research methodology for nursing. Int J Nurs Stud. 2001;38(2):195-200.

514. Tonna A, McCaig D, Diack L, West B, Stewart D. Development of consensus guidance to facilitate service redesign around pharmacist prescribing in UK hospital practice. Int J Clin Pharm. 2014.

515. Brown M. Perspectives on outcome: what disability insiders and outsiders each bring to the assessment table. Arch Phys Med Rehabil. 2009;90(11 Suppl):S36-40.

516. Brasel KJ, Deroon-Cassini T, Bradley CT. Injury severity and quality of life: whose perspective is important? J Trauma. 2010;68(2):263-8.

517. Anke AG, Fugl-Meyer AR. Life satisfaction several years after severe multiple trauma--a retrospective investigation. Clin Rehabil. 2003;17(4):431-42.

518. Van Horn ER. Recovery from traumatic injury: Trauma patients' perceptions of facilitators and barriers. International Journal of Orthopaedic and Trauma Nursing. 2013;17(4):180-9.

519. Gooberman-Hill R, Fox R. What can qualitative approaches bring to trauma outcome research? Injury. 2011;42(4):321-3.

520. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. Health Technol Assess. 1998;2(14):i-iv, 1-74.

521. Hawker GA, Davis AM, French MR, Cibere J, Jordan JM, March L, et al. Development and preliminary psychometric testing of a new OA pain measure--an OARSI/OMERACT initiative. Osteoarthritis Cartilage. 2008;16(4):409-14.

522. Mir S, Carpenter C. Implementing a person-centred model of service delivery and practice in neurological rehabilitation: theoretical and practical considerations 2011;1(3):585-91.
523. Griffiths H, Jordan S. Thinking of the future and walking back to normal: an exploratory study of patients' experiences during recovery from lower limb fracture. J Adv Nurs. 1998;28(6):1276-88.
524. Rivara FP, Mackenzie EJ, Jurkovich GJ, Nathens AB, Wang J, Scharfstein DO. Prevalence of pain in patients 1 year after major trauma. Arch Surg. 2008;143(3):282-7; discussion 8.
525. Beard DJ, Aldington D. Chronic pain after trauma. Trauma. 2012;14(1):57-66.
526. Fitzharris M, Fildes B, Charlton J, Kossmann T. General health status and functional disability following injury in traffic crashes. Traffic Inj Prev. 2007;8(3):309-20.
527. Aarabi S, Longaker MT, Gurtner GC. Hypertrophic scar formation following burns and trauma: new approaches to treatment. PLoS Med. 2007;4(9):e234.
528. Ouellet M-C, Morin CM. Fatigue following traumatic brain injury: Frequency, characteristics, and associated factors. Rehabilitation Psychology. 2006;51:140-9.
529. Gorczyca R, Filip R, Walczak E. Psychological aspects of pain. Ann Agric Environ Med. 2013;0(1):23-7.
530. Lackner JM, Quigley BM. Pain catastrophizing mediates the relationship between worry and pain suffering in patients with irritable bowel syndrome. Behav Res Ther. 2005;43(7):943-57.
531. Newman MG, Llera SJ, Erickson TM, Przeworski A, Castonguay LG. Worry and generalized anxiety disorder: a review and theoretical synthesis of evidence on nature, etiology, mechanisms, and treatment. Annu Rev Clin Psychol. 2013;9:275-97.
532. Stefanopoulou E, Hirsch CR, Hayes S, Adlam A, Coker S. Are attentional control resources reduced by worry in generalized anxiety disorder? J Abnorm Psychol. 2014;123(2):330-5.
533. Brosschot JF, Gerin W, Thayer JF. The perseverative cognition hypothesis: a review of worry, prolonged stress-related physiological activation, and health. J Psychosom Res. 2006;60(2):113-24.
534. Brosschot JF, Pieper S, Thayer JF. Expanding stress theory: prolonged activation and perseverative cognition. Psychoneuroendocrinology. 2005;30(10):1043-9.
535. Mason EC, Harvey AG. Insomnia before and after treatment for anxiety and depression. J Affect Disord. 2014;168c:415-21.
536. Sunnhed R, Jansson-Frojmark M. Are changes in worry associated with treatment response in cognitive behavioral therapy for insomnia? Cogn Behav Ther. 2014;43(1):1-11.

537. O'Donnell ML, Creamer M, Holmes AC, Ellen S, McFarlane AC, Judson R, et al. Posttraumatic stress disorder after injury: does admission to intensive care unit increase risk? J Trauma. 2010;69(3):627-32.

538. Finkelstein EA, Corso PS, Miller TR. Incidence and economic burden of injuries in the United States. Oxford: Oxford University Press; 2007.

539. Soberg HL, Finset A, Bautz-Holter E, Sandvik L, Roise O. Return to work after severe multiple injuries: a multidimensional approach on status 1 and 2 years postinjury. J Trauma. 2007;62(2):471-81.

540. Andries F, Wevers CW, Wintzen AR, Busch HF, Howeler CJ, de Jager AE, et al. Vocational perspectives and neuromuscular disorders. Int J Rehabil Res. 1997;20(3):255-73.

541. Soberg HL, Finset A, Roise O, Bautz-Holter E. Identification and comparison of rehabilitation goals after multiple injuries: an ICF analysis of the patients', physiotherapists' and other allied professionals' reported goals. J Rehabil Med. 2008;40(5):340-6.

542. Cameron PA, Gabbe BJ, Cooper DJ, Walker T, Judson R, McNeil J. A statewide system of trauma care in Victoria: effect on patient survival. Med J Aust. 2008;189(10):546-50.

543. Michaels AJ, Michaels CE, Smith JS, Moon CH, Peterson C, Long WB. Outcome from injury: general health, work status, and satisfaction 12 months after trauma. J Trauma. 2000;48(5):841-8.

544. Parliament. The Disability Discrimination Act (DDA) London: HMSO; 1995 [updated 2013-07-24; cited 2014 13th August]. Available from: http://www.legislation.gov.uk/ukpga/1995/50/contents.

545. Popplewell NT, Rechel BP, Abel GA. How do adults with physical disability experience primary care? A nationwide cross-sectional survey of access among patients in England. BMJ Open. 2014;4(8):e004714.

546. Kontopantelis E, Roland M, Reeves D. Patient experience of access to primary care: identification of predictors in a national patient survey. BMC Fam Pract. 2010;11:61.

547. Brent L, Coffey A. Patient's perception of their readiness for discharge following hip fracture surgery. International Journal of Orthopaedic and Trauma Nursing. 2013;17(4):190-8.

548. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. Bmj. 2000;320(7226):50-2.

549. Friedemann-Sánchez G, Sayer NA, Pickett T. Provider perspectives on rehabilitation of patients with polytrauma. Archives of Physical Medicine & Rehabilitation. 2008;89(1):171-9.

550. Friedemann-Sánchez G, Griffin JM, Rettmann NA, Rittman M, Partin MR. Communicating information to families of polytrauma patients: a narrative literature review. Rehabil Nurs. 2008;33(5):206-13.

551. Hetherington H, Earlam RJ, Kirk CJ. The disability status of injured patients measured by the functional independence measure (FIM) and their use of rehabilitation services. Injury. 1995;26(2):97-101.

552. Scivoletto G, Farchi S, Laurenza L, Tamburella F, Molinari M. Impact of multiple injuries on functional and neurological outcomes of patients with spinal cord injury. Scand J Trauma Resusc Emerg Med. 2013;21:42.

553. Kripalani S, Jackson AT, Schnipper JL, Coleman EA. Promoting effective transitions of care at hospital discharge: A review of key issues for hospitalists. Journal of Hospital Medicine. 2007;2(5):314-23.

554. Jordan J, Dowswell T, Harrison S, Lilford RJ, Mort M. Health needs assessment. Whose priorities? Listening to users and the public. Bmj. 1998;316(7145):1668-70.

555. Kuipers P, Foster M, Smith S, Fleming J. Using ICF-Environment factors to enhance the continuum of outpatient ABI rehabilitation: an exploratory study. Disabil Rehabil. 2009;31(2):144-51.

556. Aiachini B, Pisoni C, Cieza A, Cazzulani B, Giustini A, Pistarini C. Developing ICF core set for subjects with traumatic brain injury: an Italian clinical perspective. Eur J Phys Rehabil Med. 2010;46(1):27-36.

557. McVeigh SA, Hitzig SL, Craven BC. Influence of sport participation on community integration and quality of life: a comparison between sport participants and non-sport participants with spinal cord injury. J Spinal Cord Med. 2009;32(2):115-24.

558. Kehn M, Kroll T. Staying physically active after spinal cord injury: a qualitative exploration of barriers and facilitators to exercise participation. BMC Public Health. 2009;9:168.

559. NICE NIfHaCE. Stroke Rehabilitation (CG162). London: NICE; 2013.

560. DH DoH. NSF for Long Term Conditions. London: Department of Health; 2005.

561. NHS England N. Trauma Quality Improvement Network System (TQuINS) 2014 [cited 2015 26th March]. Available from: https://www.tquins.nhs.uk/.

562. DH DoHPbRt. Payment by Results Guidance for 2013-14 London: Department of Health; 2013 [cited 2014 5th September]. This guidance supports planning for the implementation of Payment by Results 2013-14]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214902/PbR-Guidance-2013-14.pdf.

563. Ho AM, Karmakar MK, Critchley LA. Acute pain management of patients with multiple fractured ribs: a focus on regional techniques. Curr Opin Crit Care. 2011;17(4):323-7.

564. Mohta M, Verma P, Saxena AK, Sethi AK, Tyagi A, Girotra G. Prospective, randomized comparison of continuous thoracic epidural and thoracic paravertebral infusion in patients with unilateral multiple fractured ribs--a pilot study. J Trauma. 66. United States2009. p. 1096-101.

565. Ding X, Jin S, Niu X, Ren H, Fu S, Li Q. A comparison of the analgesia efficacy and side effects of paravertebral compared with epidural blockade for thoracotomy: an updated meta-analysis. PLoS One. 9. United States2014. p. e96233.

566. Cohen SP, Christo PJ, Moroz L. Pain Management in Trauma Patients. American Journal of Physical Medicine & Rehabilitation. 2004;83(2):142-61.

567. Dijkstra BM, Berben SA, van Dongen RT, Schoonhoven L. Review on pharmacological pain management in trauma patients in (pre-hospital) emergency medicine in the Netherlands. Eur J Pain. 2014;18(1):3-19.

568. Bolton MA, Lobben I, Stern TA. The impact of body image on patient care. Prim Care Companion J Clin Psychiatry. 2010;12(2).

569. Wise EK, Hoffman JM, Powell JM, Bombardier CH, Bell KR. Benefits of exercise maintenance after traumatic brain injury. Arch Phys Med Rehabil. 93. United States: 2012 American Congress of Rehabilitation Medicine. Published by Elsevier Inc; 2012. p. 1319-23.

570. Archer T. Influence of physical exercise on traumatic brain injury deficits: scaffolding effect. Neurotox Res. 2012;21(4):418-34.

571. Archer T, Svensson K, Alricsson M. Physical exercise ameliorates deficits induced by traumatic brain injury. Acta Neurol Scand. 2012;125(5):293-302.

572. Connolly B, Denehy L, Brett S, Elliott D, Hart N. Exercise rehabilitation following hospital discharge in survivors of critical illness: an integrative review. Crit Care. 16. England2012. p. 226.

573. Radford K, Phillips J, Drummond A, Sach T, Walker M, Tyerman A, et al. Return to work after traumatic brain injury: cohort comparison and economic evaluation. Brain Inj. 2013;27(5):507-20.

574. Khadka J, McAlinden C, Gothwal VK, Lamoureux EL, Pesudovs K. The importance of rating scale design in the measurement of patient-reported outcomes using questionnaires or item banks. Invest Ophthalmol Vis Sci. 2012;53(7):4042-54.

575. Reeve BB, Hays RD, Bjorner JB, Cook KF, Crane PK, Teresi JA, et al. Psychometric evaluation and calibration of health-related quality of life item banks: plans for the

Patient-Reported Outcomes Measurement Information System (PROMIS). Med Care. 2007;45(5 Suppl 1):S22-31.

576. Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. J Clin Epidemiol. 2010;63(11):1179-94.

577. Pollard B, Dixon D, Dieppe P, Johnston M. Measuring the ICF components of impairment, activity limitation and participation restriction: an item analysis using classical test theory and item response theory. Health Qual Life Outcomes. 2009;7:41.

578. Cano SJ, Barrett LE, Zajicek JP, Hobart JC. Beyond the reach of traditional analyses: using Rasch to evaluate the DASH in people with multiple sclerosis. Mult Scler. 2011;17(2):214-22.

579. Avery LM, Russell DJ, Raina PS, Walter SD, Rosenbaum PL. Rasch analysis of the Gross Motor Function Measure: validating the assumptions of the Rasch model to create an interval-level measure. Arch Phys Med Rehabil. 2003;84(5):697-705.

580. Chen HF, Lin KC, Wu CY, Chen CL. Rasch validation and predictive validity of the action research arm test in patients receiving stroke rehabilitation. Arch Phys Med Rehabil. 2012;93(6):1039-45.

581. Cieza A, Stucki G. Content comparison of health-related quality of life (HRQOL) instruments based on the international classification of functioning, disability and health (ICF). Qual Life Res. 2005;14(5):1225-37.

582. Fayed N, Cieza A, Bickenbach JE. Linking health and health-related information to the ICF: a systematic review of the literature from 2001 to 2008. Disabil Rehabil. 2011;33(21-22):1941-51.

583. Cieza A, Hilfiker R, Boonen A, Chatterji S, Kostanjsek N, Ustun BT, et al. Items from patient-oriented instruments can be integrated into interval scales to operationalize categories of the International Classification of Functioning, Disability and Health. J Clin Epidemiol. 2009;62(9):912-21, 21.e1-3.

584. Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. Bmj. 2008;337:a1020.

585. Brink PJ, Edgecombe N. What is becoming of ethnography? Qual Health Res. 2003;13(7):1028-30.

586. Cooper S, Endacott R, Chapman Y. Qualitative research: specific designs for qualitative research in emergency care? Emerg Med J. 2009;26(11):773-6.

587. Brown M. Participation: the insider's perspective. Arch Phys Med Rehabil. 2010;91(9 Suppl):S34-7.

588. Pinnegar S, Daynes JG. *Handbook of narrative inquiry: Mapping a methodology*. Thousand Oaks, CA: Sage Publications Inc; 2006.

589. Barbour RS. Making sense of focus groups. Med Educ. 2005;39(7):742-50.

590. Bender DE, Ewbank D. The focus group as a tool for health research: issues in design and analysis. Health Transit Rev. 1994;4(1):63-80.

591. Hieblinger R, Coenen M, Stucki G, Winkelmann A, Cieza A. Validation of the International Classification of Functioning, Disability and Health Core Set for chronic widespread pain from the perspective of fibromyalgia patients. Arthritis Res Ther. 2009;11(3):R67.

592. Coenen M, Cieza A, Stamm TA, Amann E, Kollerits B, Stucki G. Validation of the International Classification of Functioning, Disability and Health (ICF) Core Set for rheumatoid arthritis from the patient perspective using focus groups. Arthritis Res Ther. 2006;8(4):R84.

INDEX OF APPENDICES

Appendix 1: Rehabilitation Complexity Scale –Version 2

<table>
<tr><td colspan="4">PATIENT IDENTIFICATION
Name: Hospital No: Date of score:...../...../.....
For each subscale, circle <u>highest level</u> applicable*</td></tr>
<tr><td colspan="4">BASIC CARE AND SUPPORT NEEDS
Describes the approximate level of intervention required for basic self-care</td></tr>
<tr><td>C 0</td><td colspan="3">Largely independent in basic care activities</td></tr>
<tr><td>C 1</td><td colspan="3">Requires help from 1 person for most basic care needs</td></tr>
<tr><td>C 2</td><td colspan="3">Requires help from 2 people for most basic care needs</td></tr>
<tr><td>C 3</td><td colspan="3">Requires help from >2 people for basic care needs
OR Requires constant 1:1 supervision</td></tr>
<tr><td colspan="4">SKILLED NURSING NEEDS
Describes the level of intervention required from qualified or skilled rehab nursing staff</td></tr>
<tr><td>N 0</td><td colspan="3">No needs for skilled nursing</td></tr>
<tr><td>N 1</td><td colspan="3">Requires intervention from a qualified nurse (e.g. for monitoring, medication, dressings etc)</td></tr>
<tr><td>N 2</td><td colspan="3">Requires intervention from trained rehabilitation nursing staff</td></tr>
<tr><td>N 3</td><td colspan="3">Requires highly specialist nursing care (e.g. for tracheostomy, behavioural management etc)</td></tr>
<tr><td colspan="4">THERAPY NEEDS
Describes the approximate level of input that is required from <u>therapy</u> disciplines</td></tr>
<tr><td colspan="4">Disciplines: State number of different <u>therapy</u> disciplines required to be <u>actively</u> involved in <u>treatment</u></td></tr>
<tr><td>TD 0</td><td>0</td><td rowspan="4">Tick therapy disciplines involved:
□ Physio
□ O/T
□ SLT
□ Dietetics
□ Social work</td><td rowspan="4">□ Psychology
□ Counselling
□ Music/art therapy
□ Play therapy</td><td rowspan="4">□ Orthotics
□ Prosthetics
□ Rehab Engineer
□ Other:</td></tr>
<tr><td>TD 1</td><td>1 disciplines only</td></tr>
<tr><td>TD 2</td><td>2-3 disciplines</td></tr>
<tr><td>TD 3</td><td>≥4 disciplines</td></tr>
<tr><td colspan="4">Intensity: State overall intensity of <u>trained</u> therapy intervention required</td></tr>
<tr><td>TI 0</td><td colspan="3">No therapy intervention (or<1 hour total/week - Rehab needs met by nursing/care staff or self-exercise programme)</td></tr>
<tr><td>TI 1</td><td colspan="3">Low level – less than daily (eg assessment / review / maintenance / supervision) OR Group therapy only</td></tr>
<tr><td>TI 2</td><td colspan="3">Moderate – daily intervention 1:1 (+/- assistant) OR <u>very intensive</u> Group programme of ≥6 hours/day</td></tr>
<tr><td>TI 3</td><td colspan="3">High level – very intensive 1:1 intervention (eg 2 trained therapists to treat, or total 1:1 therapy >25 hrs/week)</td></tr>
<tr><td>Total</td><td colspan="3">Total T score (TD + TI) :.....</td></tr>
<tr><td colspan="4">MEDICAL NEEDS
Describes the approximate level of medical care environment required for medical/surgical management</td></tr>
<tr><td>M 0</td><td colspan="3">No active medical intervention
(Could be managed by GP on basis of occasional visits)</td></tr>
<tr><td>M 1</td><td colspan="3">Basic investigation / monitoring / treatment
(Requiring non-acute hospital care,
Could be delivered in a community hospital with day time medical cover)</td></tr>
<tr><td>M 2</td><td colspan="3">Specialist medical intervention – for diagnosis or management/procedures
(Requiring in-patient hospital care in DGH or specialist hospital setting)</td></tr>
<tr><td>M 3</td><td colspan="3">Acutely sick or potentially unstable medical condition
(Requiring 24 hour on-site acute medical cover)</td></tr>
<tr><td>TOTAL</td><td colspan="3">C: N: T: M : Summed score: /15</td></tr>
</table>

Appendix 2: Barthel Index 100 point and 20 point scale

Patient Name: _____ **Rater:** _____ **Date:** __/__/__ __:__	
100 point scale	**20 point scale**
Feeding 0 = unable 5 = needs help cutting, spreading or modified diet 10 = independent	**Feeding** 0 = unable 1 = needs help cutting, spreading or modified diet 2 = independent
Bathing 0 = dependent 5 = independent (or in shower)	**Bathing** 0 = dependent 1 = independent (or in shower)
Grooming 0 = needs to help with personal care 5 = independent face/hair/teeth/shaving	**Grooming** 0 = needs to help with personal care 1 = independent face/hair/teeth/shaving
Dressing 0 = dependent 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	**Dressing** 0 = dependent 1 = needs help but can do about half unaided 2 = independent (including buttons, zips, laces, etc.)
Bowels 0 = incontinent (or needs to be given enemas) 5 = occasional accident 10 = continent	**Bowels** 0 = incontinent (or needs to be given enemas) 1 = occasional accident 2 = continent
Bladder 0 = incontinent, or catheterized and unable to manage alone 5 = occasional accident 10 = continent	**Bladder** 0 = incontinent, or catheterized and unable to manage alone 1 = occasional accident 2 = continent
Toilet Use 0 = dependent 5 = needs some help, but can do something alone 10 = independent (on and off, dressing, wiping)	**Toilet Use** 0 = dependent 1 = needs some help, but can do something alone 2 = independent (on and off, dressing, wiping)
Transfers (bed to chair and back) 0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	**Transfers (bed to chair and back)** 0 = unable, no sitting balance 1 = major help (one or two people, physical), can sit 2 = minor help (verbal or physical) 3 = independent

Mobility (on level surfaces) 0 = immobile or < 50 yards 5 = wheelchair independent, including corners, > 50 yards 10 = walks with help of one person (verbal or physical) > 50 yards 15 = independent (but may use any aid; for example, stick) > 50 yards	**Mobility (on level surfaces)** 0 = immobile or < 50 yards 1 = wheelchair independent, including corners, > 50 yards 2 = walks with help of one person (verbal or physical) > 50 yards 3 = independent (but may use any aid; for example, stick) > 50 yards
Stairs 0 = unable 5 = needs help (verbal, physical, carrying aid) 10 = independent	**Stairs** 0 = unable 1 = needs help (verbal, physical, carrying aid) 2 = independent
TOTAL (0 – 100)	**TOTAL (0-20)**

Appendix 3: Rehabilitation Complexity Scale Extended (RCS-E)

	CARE: Standard rehab needs	RISK: Cognitive behavioural needs
C 0	Largely **independent** in basic care activities	**No risk -** Standard observations only Able to go out unescorted
C 1	Requires **help from 1 person** for most basic care needs	**Low risk –** standard observations only But **requires escorting** outside the unit
C 2	Requires **help from 2 people** for most basic care needs	**Medium risk – above** standard observations OR **managed under MHA section**
C 3	Requires **help from ≥3 people** for basic care needs	**High risk – above** standard observations AND **managed under MHA section**
C 4	Requires constant **1:1 supervision** **–** for safety or behavioural management	**Very high risk** Requires **constant 1:1 supervision**

SKILLED NURSING NEEDS
Describes the level of intervention required from qualified or skilled rehab nursing staff

N 0	No needs for skilled nursing	**Tick nursing disciplines required:**
N 1	Requires intervention from a **qualified nurse** (e.g. for monitoring, medication, dressings etc)	□ General registered nursing □ Rehab-trained nurses □ Mental Health (RMN) □ Palliative care nursing □ Specialist neuro nurse (eg MS, PD, MND) State subspecialty…… □ Other
N 2	Requires intervention from **trained rehabilitation nursing staff** and/or **mental health nurses**	
N 3	Requires **highly specialist nursing care** (e.g. for tracheostomy, behavioural management etc)	

MEDICAL NEEDS
Describes the approximate level of medical care environment required for medical/surgical management

M 0	**No active medical intervention** (Could be managed by GP on basis of occasional visits)	**Tick medical interventions required:**
M 1	**Basic investigation / monitoring / treatment** (Requiring non-acute hospital care, could be delivered in a community hospital with day time medical cover)	□ Blood tests □ Imaging (CT / MRI) □ Other Investigation State type……. □ Medication adjustment / monitoring □ Surgical procedure (eg tenotomy) State type……. □ Medical procedure (eg Botulinum toxin) State type……. □ Specialist opinion State discipline…….
M 2	**Specialist medical / psychiatric intervention – for diagnosis or management/procedures** (Requiring in-patient hospital care in (DGH or specialist)	
M 3	**Acutely sick or potentially unstable medical /psychiatric condition** (Requiring 24 hour on-site acute medical / psychiatric cover)	

THERAPY NEEDS

Describes the approximate level of input that is required from therapy disciplines

Therapy Disciplines: State **number of different therapy disciplines** required to be actively involved in treatment

TD 0	**0**	**Tick therapy disciplines required:**		
TD 1	**1** disciplines only	□ Physio □ O/T □ SLT □ Dietetics □ Social work □ Other	□ Psychology □ Counselling □ Music/art therapy □ Play therapy/school □ DEA/Jobcentre Plus □ Recreational therapy □ Other	□ Orthotics □ Prosthetics □ Rehab Engineer □ Other:
TD 2	**2-3** disciplines			
TD 3	**4-5** disciplines			
TD 4	**≥6** disciplines			

Therapy Intensity: State **overall intensity of trained therapy intervention** required from team as a whole

TI 0	**No therapy intervention** (or<1 hour total/week - Rehab needs met by nursing/care staff or self-exercise programme)
TI 1	Low level – **less than daily** (eg assessment / review / maintenance / supervision) OR **Group therapy only**
TI 2	Moderate – **daily intervention - individual sessions with one person** to treat for most sessions OR **very intensive Group programme** of ≥6 hours/day
TI 3	High level – **Daily intervention with therapist PLUS assistant and/or additional group sessions**
TI 4	Very High level – **very intensive** (eg 2 trained therapists to treat, or total 1:1 therapy >30 hrs/week)
Total	**Total T score (TD + TI) :……**

EQUIPMENT NEEDS

Describes the requirements for personal equipment

E 0	**No needs** for special equipment	Basic Special Equipment	Highly Specialist Equiment
E 1	Requires **basic special equipment**	□ Wheelchair/seating □ Pressure cushion □ Special mattress □ Standing frame □ off-shelf orthotic □ Other……	□ Environmental control □ Communication aid □ Customised seating □ Customised standing aid □ Customised orthotic □ Assisted Ventilation □ Other……
E 2	Requires **highly specialist equipmen**t (eg electronic assistive technology or highly customized equipment)		

Appendix 4: European Quality of Life Scale (EuroQol)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about ❑
I have some problems in walking about ❑
I am confined to bed ❑

Self-Care

I have no problems with self-care ❑
I have some problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

Usual Activities (e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities ❑
I have some problems with performing my usual activities ❑
I am unable to perform my usual activities ❑

Pain/Discomfort

I have no pain or discomfort ❑
I have moderate pain or discomfort ❑
I have extreme pain or discomfort ❑

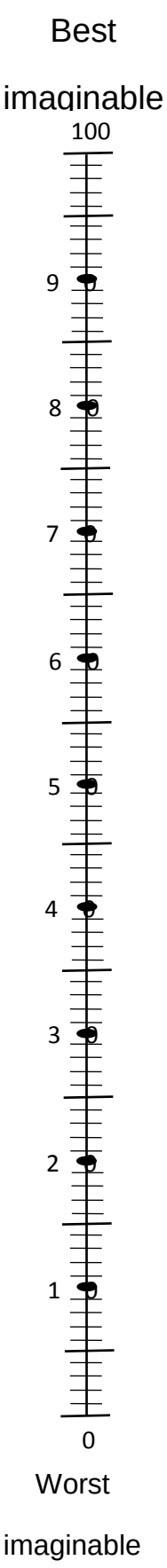
Anxiety/Depression

I am not anxious or depressed ❑
I am moderately anxious or depressed ❑
I am extremely anxious or depressed ❑

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



Appendix 5: GRADE summary of articles included in the systematic review

Source	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Ballabeni P; Burrus C; Luthi F; Gobelet C; Deriaz O (2011)	Prospective cohort study (*n=391)* Switzerland	To evaluate the association between recall of previous work environment and return to work (RTW) after hospitalisation in a rehabilitation hospital.	• Karasek's 31-item Job Content Questionnaire (JCQ)	People were less likely to return to work 1 year after hospital discharge if they perceived work to be of a higher physical demand. Social support at work was positively associated with return to work at all-time points.	**Quality rating =** Low **Risk of bias: Lack of blinding, i**ndirectness (comparing different occupations) and inconsistent results (difference in population) **Other bias:** Recall bias (self-report measures)
Baranyi *et al.*(2010)	Prospective cohort study (*n*=52*)* Germany	Evaluation of accident-related posttraumatic stress disorder (PTSD), and health-related quality of life.	• German version of the Clinician-Administered PTSD Scale (CAPS) • Syndrom-Kurz Test (SKT) • Beck Depression Inventory (BDI), • Impact of Events Sale (IES) • Dissociative Experience Scale (DES) • Medical Outcomes Study Short Form Health Survey (SF-36)	Patients with poly-trauma, needs a biopsychosocial conceptual framework to reduce psychiatric morbidity following trauma surgery in general hospitals.	**Quality rating =** Low **Risk of bias:** Inconsistent results due to small sample size and bias, prognostic imbalance. **Other bias:** Study design, number of instruments used, loss to follow up.

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Christensen MC; Banner C; Lefering R; Vallejo-Torres L; Morris S (2011)	Randomized control trial (n=347) Denmark	To determine risk factors of poor quality of life following traumatic injuries.	• Polytrauma Outcome Chart consisting of the • Glasgow Outcome Scale (GOC) • European Quality of Life Questionaire (EQ-5D) • SF-36 • Trauma Outcome Profile	Demographic and socioeconomic characteristics as well and type of injury, and treatment received can predict quality of life.	**Quality rating =** Moderate **Risk of bias:** >20% loss to follow up, **Other bias:** Recall bias (self-report measures)
Derrett S, Davie G, Ameratunga S, Langley J. (2010)	Prospective cohort study (n=111) New Zealand	To evaluate the feasibility of collecting pre and post-injury data	• WHODAS II • EQ5D	The recruitment and interview methods were both feasible and acceptable to participants.	**Quality rating** = Low **Risk of bias:** >20% loss to follow up, prognostic imbalance, lack of internal controls. **Other bias:** Recall bias (self-report measures)
Franzén C; Brulin C; Stenlund H; Björnstig U (2009)	Randomised control trial study (n=568) Sweden	To investigate whether nursing intervention via telephone follow-up can improve quality of life of injured road users.	• EQ-5D	Nursing intervention via telephone follow-up is effective at increasing the quality of life of injured road users. More research is needed to evaluate early interventions for recovery.	**Quality rating =** Low **Risk of bias:** No allocation concealment. Unclear methods used for randomisation. No blinding **Other bias:** Recall bias (self-report measures). >20% loss to follow up at 6 months

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Gabbe BJ, Simpson PM, Sutherland AM, Wolfe R, Lyons RA, Cameron PA. (2013)	Prospective cohort study (n=617) Australia	To evaluate recovery after major trauma over a 24-months.	• SF-12 • Glasgow Outcome Scale-Extended (GOS-E)	There was a variation in the rate of recovery for some subgroups and different patterns of recovery. Time points for follow up and requires careful consideration.	**Quality rating =** Low **Risk of bias:** >20% loss to follow up. prognostic imbalance, lack of internal controls. **Other bias:** Study design, recall bias (self-report measures), publication bias
Gabbe BJ, Simpson PM, Sutherland AM, Wolfe R, Fitzgerald MC, Judson R, Cameron PA. (2012)	Retrospective database review (n=4986) Australia	To describe outcomes of major trauma survivors managed in an organized trauma system.	• Glasgow Outcome Scale-Extended (GOSE).	Cases managed at Major Trauma T Centres (level-1 trauma centres) demonstrated better functional outcomes which improved over time.	**Quality rating =** Low **Risk of bias:** Study design, prognostic imbalance, lack of internal controls. **Other bias:** Recall bias (self-report measures)
Gabbe BJ, Cameron PA, Hannaford AP, Sutherland AM, McNeil JJ. (2006).	Prospective cohort study (n=662) Australia	To provide a broad description of the long-term outcomes of major trauma patients and establish the follow-up rate of registry patients.	• Modified FIM	Patients can be followed up using a trauma registry although more sensitive outcome instruments are required	**Quality rating =** Low **Risk of bias:** >20% loss to follow up. **Other bias:** Study design, no blinding or allocation concealment, recall bias (self-report measures), insensitive outcome measure- modified FIM

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Harris IA, Young JM, Rae H, Jalaludin BB, Solomon MJ. (2008)	Prospective cohort study (n=355) Australia	To explore potential predictors of general health after major physical trauma.	• SF-36	Worse physical outcomes often relates to injury compensation claims while improved physical outcome relates to time from injury and lower injury severity.	**Quality rating =** Low **Risk of bias:** Reporting bias – inconsistent results after patient refusal and exclusion **Other bias:** Study design, no blinding or allocation concealment, recall bias (self-report measures).
Holtslag HR; van Beeck EF; Lindeman E; Leenen LP (2007).	Prospective cohort study (n=335) The Netherlands	To describe the long-term functional consequences from major trauma.	• Glasgow Outcome Scale (GOS) • EuroQol (EQ-5D) Head injury symptom checklist (HISC).	The important independent predictors of long-term functional consequences after major trauma are injury localization, educational level.	**Quality rating =** Low **Risk of bias:** No blinding, prognostic imbalance, lack of internal controls. **Other bias:** Study design and dichotomising data
Holtslag H; Buskens E; Rommers C; Prevo A; van der Werken C (2006)	Prospective cohort study (n=186) The Netherlands	To measure functional recovery across several domains of daily living.	• Glasgow Outcome Scale (GOS) • Groningen Activity Restriction Score (GARS) • Sickness Impact Profile-136 (SIP) • Short Form-36 (SF-36).	Functional outcome instruments do not accurately measure log term restrictions in the level of activities and participation. Mobility is severely restricted in lower extremity poly trauma patients for a significant period after injury.	**Quality rating =** Low **Risk of bias:** Study design **Other bias:** Loss to follow up, lack of internal controls. recall bias (self-report measures)

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Jackson JC; Obremskey W; Bauer R; Greevy R; Cotton BA; Anderson V; Song Y; Ely EW (2007).	Prospective cohort study (n=58) USA	To determine the prevalence of emotional and functional difficulties as well as cognitive impairment in trauma patients in intensive without intracranial hemorrhage	• Informant Questionnaire of Cognitive Decline in the Elderly-Short Form (IQCODE-SF) • SF-36 • Beck's Depression Inventory • Katz Index of Independence in Activities of Daily Living. Activities • Davidson Trauma Scale • Beck's Anxiety Inventory • Functional Activities Questionnaire (FAQ) • Awareness questionnaire	Cognitive impairment is present in trauma patients with skull fractures, concussions and those without intra cranial haemorrhage. Poor quality of life, functional deficits and an inability to return to work resulted due to cognitive impairment.	**Quality rating =** Low **Risk of bias:** Study design and self-complete questionnaires, recall bias **Other bias:** Inconsistent results in terms of differences in patient population, imprecision – small sample size. Prognostic imbalance
Kiely JM; Brasel KJ; Weidner KL; Guse CE; Weigelt JA (2006)	Prospective cohort study (n=123) USA	To evaluate predictor of quality of life 6 months post injury.	• SF-36 • FIM • PTSD Checklist (PCL) • Centre for Epidemiologic Studies Depression Scale (*CES-D*-10)	Interventions should be targeted to improve physical functioning, reduce depression and post traumatic stress and provide adequate social support.	**Quality rating =** Low **Risk of bias:** Study design, no blinding. Prognostic imbalance, lack of internal controls. **Other bias:** Recall bias (self-report measures). Reporting bias >20% loss to follow up
Langley J, Derrett S, Davie G, Ameratunga S, Wyeth E (2011).	Prospective cohort study (*n=2856)* New Zealand	To evaluate short term functional outcomes following injury	• EQ-5D	Patients with minor injuries may have worse outcome due to pre-injury socio-demographic and health characteristics and should be included in trauma follow up.	**Quality rating =** Low **Risk of bias:** Study design, no blinding, prognostic imbalance **Other bias:** Recall bias (self-report measures).

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Livingston DH; Tripp T; Biggs C; Lavery RF (2009)	Prospective cohort study (n=100)	To evaluate long term outcome of severe injury following intensive care admission	• GOS • FIM • Modified FIM	Even at 3 years after severe sinjury people continue to have significant impairments including inability to return to work or regain previous levels of activity. Reintegration into society is limited.	**Quality rating =** Low **Risk of bias:** Study design, dichotomising scores **Other bias:** Reporting bias, >20% loss to follow up. Recall bias (self-report measures).
Mackenzie EJ; Rivara FP; Jurkovich GJ; Nathens AB; Egleston BL; Salkever DS; Frey KP; Scharfstein DO (2008).	Retrospective cohort study (n=1389) USA	To evaluate the effectiveness of trauma centres to improve functional outcomes, especially for patients with major lower-limb trauma	• SF-36 • Musculoskeletal Function Assessment (MFA) –mobility subscale • Center for Epidemiologic Studies Depression Scale (CESD-R)	Patients who sustain high-energy lower-limb trauma benefit from treatment at a level-I trauma centre.	**Quality rating =** Low **Risk of bias:** Study design, dichotomising scores, prognostic imbalance, lack of internal controls. **Other bias:** Reporting bias. Recall bias (self-report measures).
Orwelius L.,Bergkvist M.,Nordlund A.,Simonsson E.,Nordlund P.,Backman C.,Sjoberg F. (2012)	Prospective multicenter study (n=108) Sweden	To investigate HRQoL after trauma and specifically evaluate the impact of ICU-related, socio demographic factors and pre existing disease,	• SF-36	Quality of life is reduced at 2 years, especially physiological recovery likely due to pre-existing disease.	**Quality rating =** Low **Risk of bias:** Study design, lack if internal controls. **Other bias:** Reporting bias. Recall bias (self-report measures). Reporting bias >20% loss to follow up.

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Pape HC, Probst C, Lohse R, Zelle BA, Panzica M, Stalp M, Steel JL, Duhme HM, Pfeifer R, Krettek C, Sittaro NA (2010).	Prospective cohort study (n=637) Germany	To evaluate if reduced functional and psychosocial outcome can be contributed to certain injury patterns.	• SF-12 • Hannover Score for Poly-trauma Outcome, HASPOC	Traumatic lower extremity amputation, initial abbreviated injury scale score and spinal injuries result in worse outcome at ten year follow up.	**Quality rating =** Low **Risk of bias:** prognostic imbalance, lack of internal controls. **Other bias:** Recall bias (self-report measures). Reporting bias >20% loss to follow up. Questionable validity and reliability of HASPOC tool.
Pirente N.; Blum C.; Wortberg S.; Bostanci S.; Berger E.; Lefering R.; Bouillon B.; Rehm K.E.; Neugebauer E.A.M. (2007)	Randomised control trial (n=171) Germany	To evaluate if early cognitive behavioural therapy will improve quality of life if multi-trauma patients.	• Beck's Depression Inventory (BDI) • SF-36 • State-Trait Anxiety Inventory (STAI) • Symptom Checklist 90-Revised (SCL 90R) • Social support Questionnaire (Fragebogen zur Sozialen Unterstützung; F-SOZU-22)	Cognitive therapy is not effective in improving overall HRQOL of severely injured patients early on although it shows promising effects on anxiety and depression at 12 months.	**Quality rating =** Low **Risk of bias:** No blinding of research therapist **Other bias:** 23% of randomised patients withdrew. Recall bias (self-report measures). >20% loss to follow up at 12 months. Groups not matched despite randomisation.
Polinder S; van Beeck EF; Essink-Bot ML; Toet H; Looman CW; Mulder S; Meerding WJ (2007)	Prospective cohort study (n=3231) The Netherlands	To compare functional recovery from injury for non hospitalised and hospitalised patients.	• EQ-5D	Injured patients that are hospitalised take substantially longer to recover when compared to the 5 months recovery period of non-hospitalised patients. .	**Quality rating =** Low **Risk of bias:** Missing internal controls. **Other bias:** > 50% loss to follow up. Different group comparison

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Probst C, Zelle B, Panzica M, Lohse R, Sitarro NA, Krettek C, Pape HC (2010).	Longitudinal cohort study (n=637) Germany	To evaluate if there is a difference in outcome following trauma between genders.	• Hannover Score for Poly-trauma Outcome • Short form-12, HADS	Men suffer less psychological impairment than woman with similar injuries.	**Quality rating =** Low **Risk of bias:** Failure to control for confounding factors **Other bias:** Time since injury, measures used, difference in ample size, > 25% loss to follow up
Ringburg AN, Polinder S, van Ierland MC, Steyerberg EW, van Lieshout EM, Patka P, van Beeck EF, Schipper IB (2011).	Prospective cohort study (n=246) The Netherlands	Assess the health-related quality of life of survivors of severe trauma 1 year after injury	• Health Utilities Index (HUI) • EQ-5D	At 12 months after a traumatic injury, people continue to have poor functional outcome and quality of life.	**Quality rating =** Moderate **Risk of bias:** Study design but good tools and multivariate analysis **Other bias**:>30% loss to follow up,
Sayer NA; Chiros CE; Sigford B; Scott S; Clothier B; Pickett T; Lew HL (2008).	Retrospective cohort study (n=188) USA	To describe rehabilitation outcomes among patients who sustain blast and other injuries in Iraq and Afghanistan.	• Functional Independence Measure (FIM)	There is an ongoing need for better assessment and treatment of pain and mental health problems among patients with polytrauma and blast-related injuries.	**Quality rating** = Low. **Risk of bias**: No allocation concealment and blinding. Prognostic imbalance, lack of internal controls. **Other bias:** study design, intervention not clearly described, no sample size calculation, use of the FIM which has ceiling effect, no other disease burden or QoL measurements used

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Schwartz I, Tsenter J, Shochina M, Shiri S, Kedary M, Katz-Leurer M, Meiner Z (2007)	Retrospective cohort study (n=72) Israel	Comparison of rehabilitation outcomes of multi-trauma terror victims versus non-terror victims.	• Functional Independence Measure (FIM) • Impact of Events Scale (IES)	The reintegration and functional recovery of both groups are similar despite longer rehabilitation periods of terror victims. Both groups returned to previous occupation at a similar rate despite the terror group having higher levels of post traumatic stress.	**Quality rating** = Low. **Risk of bias**: No internal controls and prognostic imbalance. **Other bias:** study design, intervention not clearly described, no sample size calculation, use of the FIM which has ceiling effect,
Siddharthan K, Scott S, Bass E, Nelson A (2008).	Retrospective cohort study (n=116) USA	To evaluate rehabilitation outcome of people with military service-related injuries	• FIM	Pain management is essential to improve disability. Care co-ordination ensures optimal rehabilitation.	**Quality rating =** Very low **Risk of bias:** Study design, methodology, missing internal controls **Other bias:** 50% loss to follow up, reporting bias, no control for confounding factors
Soberg HL, Finset A, Bautz-Holter E, Sandvik L, Roise O (2007).	Prospective cohort study (n=100) Norway	To examine return to work and factors that predicted this for patients with severe multiple injuries.	• Brief Approach/Avoidance Coping Questionnaire • Multidimensional Health Locus of Control • Short Form-36 • World Health Organization Disability Assessment Schedule II (WHODAS-ll)	Many patients had not returned to work at 2 years due to social functioning and injury related factors.	**Quality rating** = Low. **Risk of bias**: No allocation concealment, internal controls missing **Other bias Bias**: study design, use of self-report measures (recall bias); time for follow up and questionable validity and reliability of outcome measures used.

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Soberg HL, Bautz-Holter E, Roise O, Finset A(2007)	Prospective cohort study (n=105) Norway	To assess functioning and quality of life after severe injuries.	• Short Form (SF)-36 • World Health Organization Disability Assessment Schedule II (WHODAS II)	Most life domains are affected by long-lasting functional problems after multiple traumatic injuries.	**Quality rating** = Low. **Risk of bias**: No sequence generation, allocation concealment and blinding. **Other bias Bias**: study design, use of self-report measures (recall bias); intervention not defined.
Soberg HL, Bautz-Holter E, Roise O, Finset A (2010)	Prospective cohort study (n=99) Norway	To describe mental health and posttraumatic stress symptoms (PTSS) for patients with severe multiple trauma 2 years after injury.	• SF-36 • Post-Traumatic Symptom Scale 10 (PTSS-10)	Post traumatic stress symptoms were still present in 20 % of patients at 2 years.	**Quality rating =** Low **Risk of bias:** No allocation concealment, prognostic imbalance. **Other bias:** No comparative group, reason in regards to high variances. Use of self report measures and time since injury (recall bias)
Soberg H.L.,Finset A.,Roise O.,Bautz-Holter E. (2012)	Prospective, longitudinal cohort study (n=105) Norway	To describe the recovery of physical and mental health for people with multiple traumatic injuries from injury to 5 year follow up and examine predictors of recovery.	• SF-36 • World Health Organization Disability Assessment Schedule II (WHODAS II)	Despite improvement in physical and mental health, figures remained below population norms at 5 years. Health outcomes were dependent on personal and injury-related factors.	**Quality rating =** Low **Risk of bias:** No allocation concealment, prognostic imbalance. **Other bias:** No comparative group, reason in regards to high variances. Use of self report measures and time since injury (recall bias)

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Steel J, Youssef M, Pfeifer R, Ramirez JM, Probst C, Sellei R, Zelle BA, Sittaro NA, Khalifa F, Pape HC (2010).	Prospective longitudinal cohort study (n=620) USA	To evaluate long-term consequences of multiple blunt force trauma.	• SF-12,	A broader range of sensitive measures are needed to prospectively capture consequences of brain injury. Evidence-based rehabilitation interventions are required to improve physical and psychological outcome.	**Quality rating =** Low **Risk of bias:** Prognostic imbalance, different measures of exposure/outcome. **Other bias:** Self-report measures (recall bias); time for follow up (10 years), ++ loss to follow up, patient population majority brain injury (skewed population sample)
Sutherland AG; Alexander DA; Hutchison JD (2006)	Prospective cohort study (n=200) UK	To investigated the relationship between physical and psychological recovery after musculoskeletal trauma	• General Health Questionnaire (GHQ) • Sickness Impact Profile (SIP) • Musculoskeletal Function Assessment (MFA) • SF-36	The strong correlation between impaired functional outcome and psychological recovery after musculoskeletal trauma.	**Quality rating =** Low **Risk of bias:** Failure to adequately control for confounding factors **Other bias**: > 20% loss to follow up, recall bias (self-complete questionnaires). Questionable validity of outcome measure (MAF)
Sutherland AG; Suttie S; Alexander DA; Hutchison JD (2011).	Prospective cohort study (n=104) UK	To investigate the long term recovery from post-traumatic psychopathology.	• General Health Questionnaire (GHQ) • Sickness Impact Profile (SIP) • Musculoskeletal Function Assessment (MFA) • SF-36	There is a strong relationship between ongoing psychological consequences and poor physical recovery while injury severity did not play an important role in psychological recovery.	**Quality rating =** Low **Risk of bias:** Failure to adequately control for confounding factors. **Other bias:** : > 48% loss to follow up, recall bias (self-complete questionnaires)

Author(s)	Study design, number of participants	Study objective	Standardised outcome instruments	Main findings	GRADE approach and comments
Van Aswegen H, Myezwa H, Mudzi W, Becker P (2011)	Prospective cohort study (n=42) South Africa	To evaluate quality of life of survivors of penetrating trauma in South Africa	• SF-36	Patients continued to have poor quality of life at 6 months when compared to population norms	**Quality rating =** Low **Risk of bias:** No internal controls and prognostic imbalance. **Other bias:** Reporting bias >20% follow up. Recall bias (self-report measures).
Zeckey, Christian, Hildebrand, Frank, Pape, Hans-Christoph, Mommsen, Philipp, Panzica, Martin, Zelle, Boris A., Alexander Sittaro, Nicola, Lohse, Ralf, Krettek, Christian, Probst, Christian (2011).	Prospective longitudinal cohort study (n=620) Germany	To evaluate the difference in outcome of poly trauma patients with and without head injuries.	• Hannover Score for Polytrauma Outcome (HASPOC) • Short Form 12 (SF-12) • Glasgow Outcome Scale (GOS)	When matched for injury severity and gender, poly trauma patients with head injured have worse outcome than patients without head injuries.	**Quality rating =** Low **Risk of bias:** Recruitment not clear, recall bias (self report measures). Prognostic imbalance **Other bias:** Questionable validity of outcome measure - Hannover Score for Poly trauma Outcome (HASPOC), no allocation concealment. >50% loss to follow up.

Appendix 6: Expert opinion on-line questionnaire

Dear participant

On behalf of the project team for Evaluating Rehabilitation Outcome in Severe Trauma (EROS)*: **Development of an ICF-based standard (ICF Core Set) for people with major trauma,*** we would like to thank you for taking part in this worldwide questionnaire. It has been endorsed by the ICF research branch in Switzerland.

Part I is the participant information sheet as required by the research ethics committee. Please read this for more information on the study and then complete the 5 consent questions.

Part 2 of the questionnaire will collect basic information on your professional background. This will enable a descriptive analysis of our participants.

Part 3 lists the 160 ICF categories identified in the Comprehensive ICF Core Sets for acute and post acute rehabilitation facilities in 2005 and validated in 2011. We would like you to select problems that are relevant to trauma patients in acute and post acute settings and list outstanding issues.

You will find an example of categories identified in the Delphi study by experts working with orthopaedic, neurological and cardio-vascular conditions from the Acute ICF Core Set. This example is by no means complete; it will merely give you an idea of some of the problems previously identified in expert surveys.

The survey should take approximately 10-15 minutes. You only need to complete it once.
More information on ICF Core Set development can be found at http://www.icf-research-branch.org/

We thank you in advance for your participation in this very important piece of rehabilitation research.

Yours sincerely,

Ms. Karen Hoffman
Prof. Karim Brohi
Dr. Diane Playford
Prof. Eva Grill
Dr. Martin Muller

PART 1: PARTICIPANT INFORMATION AND CONSENT

1. I confirm that I have read and understand the information sheet dated 28th October 2011 explaining the above research project and I have had the opportunity to ask questions about the project.

☐ YES

☐ NO

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

☐ YES

☐ NO

3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

☐ YES

☐ NO

4. I agree for the data collected from me to be used in future research

☐ YES

☐ NO

5. I agree to take part in the above research project.

☐ YES

☐ NO

PART 2: PROFESSIONAL BACKGROUND

The following three questions relate to your professional qualification and in what setting you see patients with traumatic injuries. This will help us identify if particular problems are more prevalent in particulate settings and ensure an equal representation of a variety of health care professionals.

1. What is your age?	☐ 20-29 years ☐ 30-45 years ☐ 46 -60 years ☐ 60 – 75 ☐ Older than 75
2. What is your gender?	☐ Male ☐ Femal
3. How long have you worked in your in your profession?	☐ 2-3 years ☐ 3-5 years ☐ 5-8 years ☐ Longer than 8 years
4. How long have you worked with patients with traumatic injuries?	☐ 2-3 years ☐ 3-5 years ☐ 5-8 years ☐ Longer than 8 years

5. What is your professional qualification?

- ☐ Dietician
- ☐ District Nurse
- ☐ General Practitioner
- ☐ Neuropsychologist
- ☐ Music Therapist
- ☐ Pharmacist
- ☐ Occupational Therapist
- ☐ Art therapist
- ☐ Psychologist
- ☐ Psychiatrist
- ☐ Physiotherapist
- ☐ Speech and language therapist
- ☐ Nurse
- ☐ Specialist nurse
- ☐ Trauma Nurse Coordinator
- ☐ Trauma Program Manager
- ☐ Manager
- ☐ Physician
- ☐ Rehabilitation Physician
- ☐ Orthopaedic surgeon
- ☐ Vascular surgeon
- ☐ Neurosurgeon
- ☐ Anaesthetist
- ☐ Maxillofacial surgeon
- ☐ Plastic surgeon
- ☐ General surgeon
- ☐ Traumatologist

Other (please specify)

6. Please indicate if you work in an acute or post-acute setting

- ☐ Acute setting (e.g. hospital where patient needs medical care)
- ☐ Post-acute setting (e.g. patient is medically stable and no longer needs to be in a hospital)

7. Acute Setting

- ☐ Major Trauma Centre (Specialist acute hospital)
- ☐ Trauma Unit (General acute hospital)
- ☐ Hospital (undefined)

Other (please specify)

8. Post-Acute Setting

- ☐ Generic in-patient rehabilitation (In-patient intermediate care)
- ☐ Specialist in patient rehabilitation (e.g. neuro or spinal rehabilitation)
- ☐ Skilled Nursing Facility
- ☐ Forensic unit
- ☐ Community rehabilitation team (e.g. community intermediate care)
- ☐ Out patients

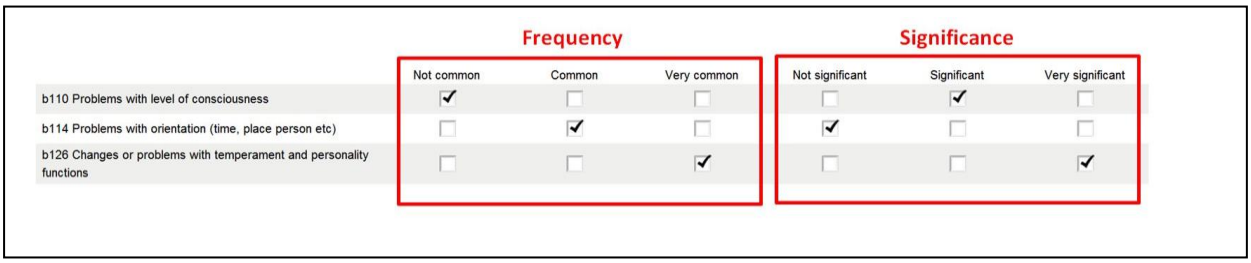
Other (please specify)

PART 3: QUESTIONNAIRE

On the previous page you indicated that you either work in an acute or post-acute setting. Please keep your clinical setting in mind (acute or post-acute) and indicate the prevalence and significance of problems you assess treat or manage. This will assist in determining the frequency that problems occur and the impact they have on people's recovery.

Please consider the implication of the problem on acute outcome if you work in an acute setting and the implication the problem have on long term outcome if you work in a post-acute setting. This will enable differentiation between acute and post-acute priorities.

For each question please select one of the first three check boxes on frequency and one in the second box indicating the severity of the problem.



	Frequency			Significance		
	Not common	Common	Very common	Not significant	Significant	Very significant
b110 Problems with level of consciousness	✓				✓	
b114 Problems with orientation (time, place person etc)		✓		✓		
b126 Changes or problems with temperament and personality functions			✓			✓

The rest of the questionnaire contains the 140 ICF categories of the Acute and Post-acute ICF Core Sets. They were previously identified by international experts working in neurological, cardio respiratory and musculoskeletal settings. The categories were determined using a three round Delphi study.

We would like to determine how applicable these categories are to trauma patients. This will facilitate greater application of the validated Acute and Post-acute ICF Core Sets in clinical practice.

Questions are presented in five categories where patients may experience problems. These are Body Functions, Body Structures, Activities and Participation, Environmental factors and Personal factors

Please keep your clinical setting in mind (acute or post-acute) and indicate the prevalence and significance of problems that you assess, treat or manage. If you think about the body and mind of individuals with trauma, what does not work the way it is supposed to? There are 77 possible problems listed.

BODY FUNCTION							
	BODY FUNCTIONS: Problems with-	**Not common**	**Common**	**Very common**	**Not Important**	**Important**	**Very Important**
b110	**Problems with level of consciousness**	◻	◻	◻	◻	◻	◻
b114	**Problems with orientation** *(time, place person etc)*	◻	◻	◻	◻	◻	◻
b126	**Changes or problems with temperament and personality functions**	◻	◻	◻	◻	◻	◻
b130	**Reduced energy and drive functions** (*fatigue, disinterest)*	◻	◻	◻	◻	◻	◻
b134	**Problems with sleep** *(too much/too little/altered pattern)*	◻	◻	◻	◻	◻	◻
b140	**Problems with attention**	◻	◻	◻	◻	◻	◻
b144	**Memory problems** *(short or long term memory)*	◻	◻	◻	◻	◻	◻
b147	**Psychomotor problems** *(coordination of sensory or cognitive processes and motor activity.)*	◻	◻	◻	◻	◻	◻
b152	**Emotional problems**	◻	◻	◻	◻	◻	◻
b156	**Perceptual problems** *(Recognizing and interpreting sensory stimuli.)*	◻	◻	◻	◻	◻	◻
b160	**Problems with thoughts or ideas**	◻	◻	◻	◻	◻	◻
b164	**Higher-level cognitive problems** (e.g. *executive functions.)*	◻	◻	◻	◻	◻	◻
b167	**Problems with recognising & using signs/symbols in language**	◻	◻	◻	◻	◻	◻
b176	**Problems sequencing complex, purposeful movements**	◻	◻	◻	◻	◻	◻
b180	**Problems with self awareness and awareness of time**	◻	◻	◻	◻	◻	◻
b210	**Problems with seeing/vision**	◻	◻	◻	◻	◻	◻
b215	**Problems with the structures adjoining the eye**	◻	◻	◻	◻	◻	◻
b230	**Problems with hearing problems**	◻	◻	◻	◻	◻	◻
b235	**Problems with vestibular control** *(Functions of the inner ear related to position, balance and movement.)*	◻	◻	◻	◻	◻	◻
b240	**Problems with hearing and vestibular functions** (e.g. *dizziness, falling, tinnitus and vertigo)*	◻	◻	◻	◻	◻	◻
b260	**Problems with proprioception**	◻	◻	◻	◻	◻	◻
b265	**Problems with touch sensation** *(tactile/texture)*	◻	◻	◻	◻	◻	◻

	BODY FUNCTIONS: Problems with-	Not common	Common	Very common	Not Important	Important	Very Important
b270	**Problems with sensation of temperature and other stimuli** *(e.g. temperature, vibration, pressure and noxious stimulus)*	◻	◻	◻	◻	◻	◻
b280	**Problems with pain**	◻	◻	◻	◻	◻	◻
b310	**Problems with voice** *(production and quality of voice and sound made through coordination of the larynx and surrounding muscles with the respiratory system)*	◻	◻	◻	◻	◻	◻
b320	**Problems with articulation** *(production of speech sounds)*	◻	◻	◻	◻	◻	◻
b340	**Problems with alternative vocalization** *(singing ,humming, screaming)*	◻	◻	◻	◻	◻	◻
b410	**Cardiac (heart) problems**	◻	◻	◻	◻	◻	◻
b415	**Problems with blood vessels**	◻	◻	◻	◻	◻	◻
b420	**Problems with blood pressure**	◻	◻	◻	◻	◻	◻
b430	**Problems with haematological system** *(blood production, oxygen and clotting)*	◻	◻	◻	◻	◻	◻
b435	**Problems with immune system**	◻	◻	◻	◻	◻	◻
b440	**Problems with respiration functions**	◻	◻	◻	◻	◻	◻
b445	**Problems with respiratory muscle functions**	◻	◻	◻	◻	◻	◻
b450	**Problems with additional respiratory functions** *(e.g. coughing, sneezing and yawning)*	◻	◻	◻	◻	◻	◻
b455	**Problems with exercise tolerance**	◻	◻	◻	◻	◻	◻
b460	**Sensation of cardiac and respiratory problems** *(e.g. sensation of missing a heart beat, palpitation*	◻	◻	◻	◻	◻	◻
b510	**Problems with Ingestion** *(eating and drinking)*	◻	◻	◻	◻	◻	◻
b515	**Problems with digestion**	◻	◻	◻	◻	◻	◻
b525	**Problems with defecation**	◻	◻	◻	◻	◻	◻
b530	**Problems with weight maintenance**	◻	◻	◻	◻	◻	◻
b535	**Problems with sensations associated with the digestive system** *(e.g. bloated, indigestion)*	◻	◻	◻	◻	◻	◻
b540	**Problems with general metabolism**	◻	◻	◻	◻	◻	◻
b545	**Problems with water, mineral and electrolyte balance**	◻	◻	◻	◻	◻	◻

	BODY FUNCTIONS: Problems with-	Not common	Common	Very common	Not Important	Important	Very Important
b610	**Problems with urinary excretory functions**	◻	◻	◻	◻	◻	◻
b620	**Problems with urination**	◻	◻	◻	◻	◻	◻
b710	**Problems with joint mobility**	◻	◻	◻	◻	◻	◻
b715	**Problems with joint stability**	◻	◻	◻	◻	◻	◻
b730	**Problems with muscle power**	◻	◻	◻	◻	◻	◻
b735	**Problems with muscle tone**	◻	◻	◻	◻	◻	◻
b740	**Problems with muscle endurance**	◻	◻	◻	◻	◻	◻
b755	**Problems with involuntary movement reactions**	◻	◻	◻	◻	◻	◻
b760	**Problems with control of voluntary movement**	◻	◻	◻	◻	◻	◻
b770	**Problems with gait pattern** *(e.g. walking, running)*	◻	◻	◻	◻	◻	◻
b780	**Problems with sensations related to muscles and movement functions**	◻	◻	◻	◻	◻	◻
b810	**Protective functions of the skin** *(e.g. temperature control)*	◻	◻	◻	◻	◻	◻
b820	**Repair functions of the skin** *(e.g. wound healing)*	◻ ◻	◻ ◻	◻ ◻	◻ ◻	◻ ◻	◻ ◻
	Other problems in <u>body functions</u> not listed: ***Only one answer per row please***						
		◻	◻	◻	◻	◻	◻
		◻	◻	◻	◻	◻	◻

BODY STRUCTURES

If you think about the body of individuals with trauma, in which BODY PARTS are their problems? There are 13 possible problems listed. Please indicate how frequently you assess, treat or manage these problems in your clinical setting and the impact these have on patient outcome (acute/post acute).

	BODY STRUCTURE Problems with -	Not common	Common	Very common	Not Important	Important	Very Important
s110	**Structures of brain**	◻	◻	◻	◻	◻	◻
s120	**Spinal cord and related structures**	◻	◻	◻	◻	◻	◻
s130	**Structures of meninges**	◻	◻	◻	◻	◻	◻
s410	**Structures of cardiovascular system**	◻	◻	◻	◻	◻	◻
s430	**Structures of respiratory system**	◻	◻	◻	◻	◻	◻
s530	**Structures of stomach**	◻	◻	◻	◻	◻	◻
s710	**Structures of head and neck region**	◻	◻	◻	◻	◻	◻
s720	**Structures of shoulder region**	◻	◻	◻	◻	◻	◻
s730	**Structures of upper extremity**	◻	◻	◻	◻	◻	◻
s740	**Structures of pelvic region**	◻	◻	◻	◻	◻	◻
s750	**Structures of lower extremity**	◻	◻	◻	◻	◻	◻
s760	**Structures of trunk**	◻	◻	◻	◻	◻	◻
s810	**Structures of areas of skin**	◻	◻	◻	◻	◻	◻
Other problems in <u>body structure</u> not listed: Only one answer per row please							

ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

If you think about the DAILY LIFE of individuals with trauma, what are their problems?. Please indicate how frequently you assess, treat or manage these problems in your clinical setting and the impact these have on patient outcome. There are 40 possible problems listed.

	ACTIVITIES AND PARTICIPATON Problems with	**Not common**	**Common**	**Very common**	**Not Important**	**Important**	**Very Important**
d110	**Problems with watching**	◻	◻	◻	◻	◻	◻
d115	**Problems with listening**	◻	◻	◻	◻	◻	◻
d120	**Problems with other purposeful sensing** *(e.g. basic senses such as feeling textures, tasting sweets or smelling flowers)*	◻	◻	◻	◻	◻	◻
d130	**Problems with copying** *(e.g. copying a gesture, a sound or the letters of an alphabet)*	◻	◻	◻	◻	◻	◻
d135	**Problems with rehearsing** *(e.g. repeating a sequence of events or symbols)*	◻	◻	◻	◻	◻	◻
d155	**Problems with acquiring skills**	◻	◻	◻	◻	◻	◻
d160	**Problems with focusing attention**	◻	◻	◻	◻	◻	◻
d166	**Problems with reading**	◻	◻	◻	◻	◻	◻
d170	**Problems with writing**	◻	◻	◻	◻	◻	◻
d175	**Problems with problem solving**	◻	◻	◻	◻	◻	◻
d177	**Problems with making decisions**	◻	◻	◻	◻	◻	◻
d230	**Problems with carrying out daily routine**	◻	◻	◻	◻	◻	◻
d240	**Problems with handling stress and other psychological demands**	◻	◻	◻	◻	◻	◻
d310	**Problems with communicating with – receiving– spoken messages**	◻	◻	◻	◻	◻	◻
d315	**Problems with communicating with – receiving – nonverbal messages**	◻	◻	◻	◻	◻	◻
d330	**Problems with speaking**	◻	◻	◻	◻	◻	◻
d335	**Problems with producing nonverbal messages** *(e.g.shaking head to indicate disagreement)*	◻	◻	◻	◻	◻	◻
d350	**Problems with conversation** *(e.g. starting, sustaining and ending a conversation)*	◻	◻	◻	◻	◻	◻
d360	**Problems with using communication devices and techniques** *(e.g. using a telephone)*	◻	◻	◻	◻	◻	◻
d410	**Problems with changing basic body position** *(e.g. kneel to stand, sit to stand)*	◻	◻	◻	◻	◻	◻

	ACTIVITIES AND PARTICIPATON Problems with	Not common	Common	Very common	Not Important	Important	Very Important
d415	**Problems with maintaining a body position** *(e.g. remaining seated/ standing for work or school)*	▫	▫	▫	▫	▫	▫
d420	**Problems with transferring oneself** *(e.g. sliding along a bench; moving from a bed to a chair)*	▫	▫	▫	▫	▫	▫
d430	**Problems with lifting and carrying objects**	▫	▫	▫	▫	▫	▫
d440	**Problems with fine hand use** *(e.g. picking up, grasping)*	▫	▫	▫	▫	▫	▫
d445	**Problems with hand and arm use** *(e.g. hand eye co-ordinatio)*	▫	▫	▫	▫	▫	▫
d450	**Problems with walking**	▫	▫	▫	▫	▫	▫
d460	**Problems with moving around in different locations** *(e.g. indoor and outdoor)*	▫	▫	▫	▫	▫	▫
d465	**Problems with moving around using equipment** *(e.g. using skates, wheelchair or a walker)*	▫	▫	▫	▫	▫	▫
d510	**Problems with washing and drying oneself**	▫	▫	▫	▫	▫	▫
d520	**Problems with caring for body parts** *(e.g. face, teeth, nails that require more than washing and drying)*	▫	▫	▫	▫	▫	▫
d530	**Problems with toileting**	▫	▫	▫	▫	▫	▫
d540	**Problems with dressing**	▫	▫	▫	▫	▫	▫
d550	**Problems with eating**	▫	▫	▫	▫	▫	▫
d560	**Problems with drinking**	▫	▫	▫	▫	▫	▫
d570	**Problems with looking after one`s health** *(e.g. balanced diet, physical activity)*	▫	▫	▫	▫	▫	▫
d760	**Problems with family relationships**	▫	▫	▫	▫	▫	▫
d870	**Problems with economic self-sufficiency** *(e.g.control over economic/financial resources)*	▫	▫	▫	▫	▫	▫
d910	**Problems with engaging in community life** *(e.g. social life, charities, service clubs etc)*	▫	▫	▫	▫	▫	▫
d930	**Problems with engaging in religion and spirituality**	▫	▫	▫	▫	▫	▫
d940	**Human rights** *(e.g.nationally and internationally recognized rights such as the right to self-determination or autonomy; and the right to control over one's destiny)*	▫	▫	▫	▫	▫	▫

Other problems with daily activities not listed: Only one answer per row please							

ENVIRONMENTAL FACTORS

This question relates to the attitudes of a variety of people that influence behaviour or actions of patients. This includes social, political and economic issues that influence individual behaviour and actions. Please indicate the prevalence and significance of these attitudes and issues and if they are supportive or restrictive. There are 13 items listed.

	ENVIRONMENTAL FACTORS Are these factors hindrances or supportive for patients with trauma?	Not common	Common	Very common	Not Important	Important	Very Important	Supportive	Restrictive
e110	**Products or substances for personal consumption and ingestion** *(e.g. natural or human-made object or substance gathered, processed or manufactured for intake)*	◻	◻	◻	◻	◻	◻	◻	◻
e115	**Products and technology for personal use in daily living** *(Equipment, products and technologies including adapted and specialized devices)*	◻	◻	◻	◻	◻	◻	◻	◻
e120	**Products and technology for personal indoor and outdoor mobility and transportation**	◻	◻	◻	◻	◻	◻	◻	◻
e125	**Products and technology for communication** *(e.g. computers, mobile phones)*	◻	◻	◻	◻	◻	◻	◻	◻
e150	**Design, construction and technology of building for public use**	◻	◻	◻	◻	◻	◻	◻	◻
e155	**Design, construction and technology of building for private use**	◻	◻	◻	◻	◻	◻	◻	◻
e225	**Climate**	◻	◻	◻	◻	◻	◻	◻	◻
e240	**Light** *(e.g. sunlight, candles, oil or paraffin lamps, fires and electricity)*	◻	◻	◻	◻	◻	◻	◻	◻
e245	**Time-related changes** *(e.g. natural, regular or predictable temporal change)*	◻	◻	◻	◻	◻	◻	◻	◻
e250	**Sound** *(e.g. banging, ringing, buzzing, in any volume that is useful/distracting)*	◻	◻	◻	◻	◻	◻	◻	◻

	ENVIRONMENTAL FACTORS Are these factors hindrances or supportive for patients with trauma?	Not common	Common	Very common	Not Important	Important	Very s	Supportive	Restrictive
e260	**Air quality** *(inside and outside buildings)*	◻	◻	◻	◻	◻	◻	◻	◻
e310	**Immediate family**	◻	◻	◻	◻	◻	◻	◻	◻
e315	**Extended family**	◻	◻	◻	◻	◻	◻	◻	◻
e320	**Friends**	◻	◻	◻	◻	◻	◻	◻	◻
e340	**Personal care providers and personal assistants**	◻	◻	◻	◻	◻	◻	◻	◻
e355	**Health care professionals**	◻	◻	◻	◻	◻	◻	◻	◻
e360	**Health related professionals** *(e.g.lawyers, social workers, teachers, architects)*	◻	◻	◻	◻	◻	◻	◻	◻
e410	**Individual attitudes of immediate family members**	◻	◻	◻	◻	◻	◻	◻	◻
e415	**Individual attitudes of extended family members**	◻	◻	◻	◻	◻	◻	◻	◻
e420	**Individual attitudes of friends**	◻	◻	◻	◻	◻	◻	◻	◻
e430	**Individual attitudes of people in positions of authority**	◻	◻	◻	◻	◻	◻	◻	◻
e440	**Individual attitudes of personal care providers and personal assistants**	◻	◻	◻	◻	◻	◻	◻	◻
e450	**Individual attitudes of health professionals**	◻	◻	◻	◻	◻	◻	◻	◻
e455	**Individual attitudes of other professionals**	◻	◻	◻	◻	◻	◻	◻	◻
e465	**Social norms, practices and ideologies**	◻	◻	◻	◻	◻	◻	◻	◻
e550	**Legal services, systems and policies** *(legislation and other law of a country)*	◻	◻	◻	◻	◻	◻	◻	◻
e555	**Associations, memberships and organizational services** *(e.g. charities)*	◻	◻	◻	◻	◻	◻	◻	◻
e570	**Social security, services, systems & policies** *(e.g. income support,tax relief, unemployment)*	◻	◻	◻	◻	◻	◻	◻	◻
e575	**General social support services** *(e.g. assistance with shopping, housework, transport, self-care and care of others, in order to function more fully in society)*	◻	◻	◻	◻	◻	◻	◻	◻
e580	**Health services, systems and policies** *(e.g. preventing and treating health problems)*	◻	◻	◻	◻	◻	◻	◻	◻
Other problems with environmental aspects not listed: Only one answer per row please									

PERSONAL FACTORS

If you think about individuals with traumatic injuries, what important personal factors either assist or prevents them from coping with their injuries? This could be gender, race, age, lifestyle, social background, education, occupation, or psychological characteristics.

Only one answer per row please

Prevents coping
Facilitates coping

FINISHED! THANK YOU VERY MUCH FOR YOUR TIME

All data stored online is secure, and anonymous.

Results of the expert survey, patient interviews and cross sectional study will be posted on the Centre for Trauma Science website.

For more information:
http://www.smd.qmul.ac.uk/research/neuro/traumascience/index.html

Please do not hesitate to contact us if you have any questions at the following email addresses: traumacoreset@gmail.com OR k.hoffman@qmul.ac.uk

Please provide your email address if you would like more information on the outcome of the project and the consensus conference.

Email address:	

Appendix 7: Topic guide for patient interviews

Below is a list of prompts to use during the interview. All the prompts will not be used if the patient covers aspects during their conversation. They are there to ensure we gain as much detail as possible without causing participant burden. In some instances behaviour will be described instead of using terminology as some people can associate with this better than medical words. An example may be *'are you anxious or depressed'* rephrased as '*are you worried, avoid certain situations or feel tired a lot of the time?'*

1. **I understand that you have had an accident; can you tell me about it? What impact has it had on you?**

2. **I would like you to think of three things –**
   - Are there any parts of your body or mind that does not work the way they used to due to your accident?
   - Does this impact you being able to do the things you need or want to do?
   - Is your physical or social environment helping you or preventing you from getting better?

3. **If you think about your <u>body and mind</u>, what does not work the way it is suppose to?**

You may want to think of things like-

- Your mental functions (concentration, memory, mood, sleep, temperament, organisation)
- Pain or change in sensation (feeling)
- Any changes in your voice and speech
- Any changes or problems with your cardiovascular system, immune system, breathing (respiratory)
- Any problems with eating food or digesting food – special diet, weight loss?
- Any problems with 'waterworks', going to the toilet, sexual functioning or reproductive functioning
- Any problems with your bones, joints, muscle strength, endurance, walking patterns, movement reactions (neuro-musculoskeletal)
- Any problems with your skin such as scars, sensation, pressure areas, wound healing

4. **If you think about your body, which <u>body parts</u> cause your problems?**
   - Any problems with your face, e.g. eyes, ears, mouth, nose etc.
   - Any problems with your head, e.g. brain
   - Any problems with your lungs or heart that you know of?
   - Any problems with your intestines, liver, pancreas, bladder or stomach?
   - Any problems with your pelvis (hips), urinary system, erectile function etc.
   - Any problems with bones, ligaments or joints anywhere in your body?
   - Any problems with your skin, hair, nails or glands?

5. **If you think about your <u>everyday life,</u> what problems do you experience? Think of things you used to do and now struggle with OR things you used to do but now avoid doing them. Describe behaviours where necessary, e.g. avoidance or anxiety…**
   - Do you have any difficulty learning new skills or remembering previous things you were able to do? Think of your ability to watch TV or read a book and remember what the story was about OR thinking and making decisions?
   - Do you have problems dealing with everyday things, e.g. doing more than one thing at a time OR managing stressful situations? Which situations are stressful?
   - Do you have any problems understanding people, following a conversation or initiating a conversation OR take down messaged/write things down incorrectly?
   - Do you have any problems moving around? E.g. using your arms, legs or hands OR using private or public transport?
   - Do you have any problem with self-care? E.g. washing and dressing yourself, eating, drinking or staying healthy?
   - Do you have any difficulty doing household tasks such as cleaning, cooking or shopping?
   - Do you have any problems with relationships or friendships, eg. With your spouse, parents, teacher etc?
   - Do you have any difficulty in participating or doing work, school, or having enough money to look after yourself and or your family?
   - Do you have any problems in participating in social, religious or community activities?

6. If you think about your environment and your living conditions, what do you find helpful or unhelpful?
   - Do you have use or have access to products or technology that helps you with communication, employment or daily living, such as a phone, assitive devices, a computer etc?
   - Does the environment effect you in any way, e.g. sound, climate, light etc?
   - Do you have any problems with support or relationships with family, friends or people in authority? Are the relationships and support helpful or not?
   - Are other people's or the societies attitudes helpful or hindering?
   - Do you have any problems with services, systems or policies such as housing system, communication services, transport services, social services, benefits, health services etc?

7. If you think about yourself, what is important about you and the way you handle your injuries? Personal strengths or weaknesses?

Additional prompts:

What does a usual day look like for you now following your accident?

Is there anything else you would like to add?

Appendix 8: Search strategy for systematic review

Search History

2. MEDLINE; exp WOUNDS AND INJURIES/; 646280 results.
1. MEDLINE; exp REHABILITATION/; 134865 results.
4. MEDLINE; 1 OR 3; 198828 results.
3. MEDLINE; rehabilitation.ti,ab; 89044 results.
5. MEDLINE; ("major trauma" OR "multiple injuries" OR "poly trauma").ti,ab; 4211 results.
7. MEDLINE; exp *"QUALITY OF LIFE"/; 44377 results.
8. MEDLINE; ("quality of life" OR "health" OR "wellbeing").ti,ab; 1009023 results.
9. MEDLINE; ("outcome measure" OR "outcome tool" OR "instrument").ti,ab [Limit to: Publication Year 2006-2012]; 44486 results.
6. MEDLINE; exp *MULTIPLE TRAUMA/; 6382 results.
10. MEDLINE; exp TREATMENT OUTCOME/ OR exp "OUTCOME ASSESSMENT (HEALTH CARE)"/; 592739 results.
12. MEDLINE; 7 OR 8; 1015515 results.
13. MEDLINE; 1 OR 3; 198828 results.
14. MEDLINE; 2 OR 5 OR 6; 647058 results.
15. MEDLINE; 11 AND 12 AND 13 AND 14 [Limit to: Publication Year 2006-2012]; 411 results.
11. MEDLINE; 9 OR 10 [Limit to: Publication Year 2006-2012]; 347987 results.
16. MEDLINE; 15 [Limit to: Publication Year 2006-2012 and (Age Groups All Adult 19 plus years) and (Languages English) and (Publication Types Clinical Trial, All or Clinical Trial, Phase I or Clinical Trial, Phase II or Clinical Trial, Phase III or Clinical Trial, Phase IV or Clinical Trial or Comparative Study or Consensus Development Conference or Consensus Development Conference, NIH or Controlled Clinical Trial or Evaluation Studies or Government Publications or Guideline or Interview or Meta Analysis or Multicenter Study or Practice Guideline or Randomized Controlled Trial or Research Support, American Recovery and Reinvestment Act or Research Support, NIH, Extramural or Research Support, NIH, Intramural or Research Support, Non US Gov't or Research Support, US Gov't, Non PHS or Research Support, US Gov't, PHS or Review or Scientific Integrity Review or Twin Study or Validation Studies)]; 237 results.

Appendix 9: ICF linking of frequently used outcome measures used in trauma research

	SF-36	EuroQol	FIM	GOS	WHODAS II	TOP	Absolute frequency (n)	Absolute frequency%	Relative frequency n	Relative frequency%
Number of studies cited in	14	7	5	5	4	1				
Number of items in measure	36	5	18	5	36	32				
Total concepts per measure	53	10	37	9	34	107				
ICF categories	23	10	29	9	24	61				
Body Function (b) n=22	6	2	10	2	3	14				
CHAPTER 1: Mental functions (b1)										
b110 Consciousness functions				1			1	17%	1	17%
b117 Intelectual functions			1	1			2	33%	2	33%
b126 Temprament and personality functions					1	2	3	50%	2	33%
b130 Energy and drive	4					3	7	117%	2	33%
b134 Sleep functions	1					1	2	33%	2	33%
b 140 Attention functions			1			3	4	67%	2	33%
b 144 Memory functions			1		1	2	4	67%	3	50%
b147 Psychomotor functions						2	2	33%	1	17%
b152 Emotional functions	5	1			1	7	14	233%	4	67%

	SF-36	EuroQol	FIM	GOS	WHODAS II	TOP	Absolute frequency (n)	Absolute frequency%	Relative frequency n	Relative frequency%
b164 Higher-level cognitive functions			2				2	33%	1	17%
b167 Mental function of language			1				1	17%	1	17%
b180 Experience of self and time functions	1					4	5	83%	2	33%
CHAPTER 2: Sensory functions and pain (b2)										
b280 Sensation of pain	2	1				14	17	283%	3	50%
CHAPTER 3:										
b330 Fluency and rhythm of speech functions			1				1	17%	1	17%
CHAPTER 4: Functions of the cardiovascular, haematological, immunological and respiratory systems										
b410 Heart functions						1	1	17%	1	17%
b455 Exercise tolerance functions						1	1	17%	1	17%

	SF-36	EuroQol	FIM	GOS	WHODAS II	TOP	Absolute frequency (n)	Absolute frequency%	Relative frequency n	Relative frequency%
CHAPTER 5: Functions of the digestive, metabolic and endocrine systems										
b525 Defecation functions			1				1	17%	1	17%
b550 Thermoregulatory functions						1	1	17%	1	17%
CHAPTER 6: Genitourinary and reproductive functions										
b610 Urination functions			1				1	17%	1	17%
b639 Urinary functions, other specified and unspecified			1				1	17%	1	17%
CHAPTER 7: Neuro musculoskeletal and movement-related functions										
b735 Muscle tone functions						1	1	17%	1	17%
Body Structure (s) n=15	0	0	0	1	0	14				
s110 Structure of brain				1			1	17%	1	17%
14 body structures mentioned in TOP						14	14	233%	1	17%

	SF-36	EuroQol	FIM	GOS	WHODAS II	TOP	Absolute frequency (n)	Absolute frequency%	Relative frequency n	Relative frequency%
Activity and Participation (d) n=45	17	8	19	6	21	29				
CHAPTER 1: Learning and applying knowledge										
d155 Acquiring a skill					2		2	33%	1	17%
d160 Focusing attention					1	2	3	50%	2	33%
d163 Thinking						2	2	33%	1	17%
d175 Solving problems			1		1	2	4	67%	3	50%
CHAPTER 2: General tasks and demands										
d220 Undertaking multiple tasks	1						1	17%	1	17%
d230 Carrying out daily routine	2					2	4	67%	2	33%
d240 Handling stress and other psychological demands	1					5	6	100%	2	33%
CHAPTER 3: Communication										
d310 Communicating with – receiving – spoken messages			1		1		2	33%	2	33%
d315 Communicating with – receiving – nonverbal messages			1				1	17%	1	17%
d335 Producing non verbal messages			1				1	17%	1	17%
d350 Conversation			1		2		3	50%	2	33%

	SF-36	EuroQol	FIM	GOS	WHODASII	TOP	Absolute frequency (n)	Absolute frequency%	Relative frequency n	Relative frequency%
CHAPTER 4: Mobility										
d410 Changing basic body position	1		2		1		4	67%	3	50%
d415 Maintaining a body position					1	1	2	33%	2	33%
d420 Transferring oneself			3				3	50%	1	17%
d430 Lifting and carrying objects	3						3	50%	1	17%
d450 Walking	3	1	1		1		6	100%	4	67%
d455 Moving around	6		3				9	150%	2	33%
d460 Moving around in different locations					2		2	33%	1	17%
d465 Moving around using equipment			1			1	2	33%	2	33%
CHAPTER 5: Self-care										
d510 Washing oneself	1	1	1		1	1	5	83%	5	83%
d520 Caring for body parts			2			1	3	50%	2	33%
d530 Toiletting			1			1	2	33%	2	33%
d540 Dressing	1	1	2		1	1	6	100%	5	83%
d550 Eating			1		1	1	3	50%	3	50%
d560 Drinking			1			1	2	33%	2	33%
d570 Looking after one's health	6					3	9	150%	2	33%

	SF-36	EuroQol	FIM	GOS	WHODAS II	TOP	Absolute frequency (n)	Absolute frequency%	Relative frequency n	Relative frequency%
CHAPTER 6: Domestic life										
d640 Doing housework	3	1		1	2	1	8	133%	5	83%
CHAPTER 7: Interpersonal interactions and relationships										
d710 Basic Interpersonal interaction	1		1			1	3	50%	3	50%
d720 Complex interpersonal interaction					1	1	2	33%	2	33%
d730 Relating with strangers					1		1	17%	1	17%
d750 Informal social relationships	1				2	1	4	67%	3	50%
d760 Family relationships	1	1	1			1	4	67%	4	67%
d770 Intimate relationships			1		1	3	5	83%	3	50%
d799 Interpersonal interaction and relationships, unspecified						1	1	17%	1	17%
CHAPTER 8: Major life areas										
d820 School education		1				1	2	33%	2	33%
d825 Vocational training				1		1	2	33%	2	33%
d830 Higher education				1		1	2	33%	2	33%
d845 Acquiring, keeping and terminating a job				1	3		4	67%	2	33%
d850 Remunerative employment	4	1		1		2	8	133%	4	67%
d855 Non-renumerative employment						1	1	17%	1	17%
d860 Basic economic transactions						1	1	17%	1	17%

d870 Economic self-sufficiency					1	1	2	33%	2	33%
	SF-36	**EuroQol**	**FIM**	**GOS**	**WHODAS II**	**TOP**	**Absolute frequency (n)**	**Absolute frequency%**	**Relative frequency n**	**Relative frequency%**
CHAPTER 9: Community, social and civic life										
d910 Community life	1			1	3		5	83%	3	50%
d920 Recreation and leisure	3	1			1	1	6	100%	4	67%
d930 Religion and spirituality					1		1	17%	1	17%
Environment (e) n=4	0	0	0	0	0	4				
CHAPTER 1 :Products and technology										
e115 Products and technology for personal daily living						2	2	33%	1	17%
CHAPTER 3: Support and relationships										
e310 Immediate family						2	2	33%	1	17%
CHAPTER 4: Attitudes										
e410 Individual attitudes of immediate family						2	2	33%	1	17%
CHAPTER 5: Services, systems and policies										
e590 Labour and employment services						1	1	17%	1	17%

Appendix 10: Qualitative approaches which were disregarded

An *ethnographic approach* explores the behaviours, social interactions and perceptions of that occur within communities, groups and teams. It provides a rich and holistic view into peoples' culture while exploring their views, actions and behaviours (584, 585). There are no specific guidance on how to carry out the research but observation and interviews are often used to generate data to develop the theory or understanding of a specific culture or social context (586). This approach is used to enable 'outsiders' (the researcher) to understand the culture from an 'insiders' (the people being observed) perspective (515, 586, 587). Ethnography is often used in disability research in an attempt to understand challenges experienced by patients and patient perception (587). Although this approach will be beneficial to explores several factors related to recovery after trauma it was discounted due to the length of time required (307) for observation and analysis.

A *narrative based approach* would consider life histories of people and possibly other important people such as parents or spouses. Its focus is usually on either one individual or a small number of individuals during which time the researcher collects and records different stories; collect information about the context of the stories; analyse them and develop a framework that makes sense (311). This approach is used to describe the story of an individual or a small group of people with chronologic unfolding of experiences, within a specific social and historical context. This approach is very time intensive and due to the level of information that needs to be collected (588). It was discounted as it was not my intention to collect life histories of trauma patients.

Phenomenology describes the meaning for several individuals of a lived experience or a phenomenon they have in common. It describes what all participants have in common while they experience the phenomenon (311, 312). This approach, and specifically interpretive phenomenology explores the essence, experience or concealed meanings of everyday life experiences (307). The description may focus on what people experience and how they experience it rather than an analysis or an explanation of their experience (311). While this approach would be of great benefit in gaining a greater understanding of the lived experience of trauma survivors, specifically due to the lack of this literature, this was not the aim of the study and this approach was thus not considered. I also did not seek to develop a theory related to trauma patients.

The *grounded theory approach* has particular benefits as it provides explicit procedures for generating research theory (307). It provides clear procedures for carrying out the research, the analysis and theory generation. Theory is generated (311) through data collection and hypothesis testing which confirms or refutes the theory (586). Purposeful theoretical sampling is used to ensure the correct sample of individuals are recruited which will help to generate the theory. Thematic analysis or content analysis may be used until saturation is reached, although some authors say this is difficult to define while developing a new theory (307, 586).

Appendix 11: Data collection methods which were disregarded

Focus Groups

Use: These can be structured or unstructured involving a small group of people who interact with each other (116) and facilitated by a researcher and possibly a research assistant. The researcher prepares some discussion points for some organisation but the focus group does not have a specific structure. Focus groups are often used to explore cultural values and beliefs about health and disease (116, 589). It can also stimulate opinions on a topic to develop an understanding of user perspective of a topic (590). Ideally, the researcher or facilitator of focus groups will blend into the background, only posing occasional contextual questions while allowing the group interaction to generate responses (590)

Advantages: Focus groups specifically rely on the process of group dynamics stimulate discussion and generate new ideas. There is an opportunity for discussion between participants with similar and opposing views which provides evidence of similarities and differences in experience and opinions. An interpretive approach is used to analyse how people understand the meaning of events of their social world (116). It is cost and time efficient and enables collection of a large amount of data in short time.

Disadvantage: The topic for a focus group should have a narrow focus to ensure participants are clear on the point of interest (590). This provides less depth and detail about experiences when compared to interviews. Focus groups can be difficult to organise in terms of getting all participants in the right place at the right time which also has cost implications in terms of travel and transportation. The facilitator requires good skills to notice high and low involvement of participants and to prevent anyone 'going off on a tangent'. Confidentiality is not maintained and some participant may not be comfortable discussing certain issues in front of strangers. This can be particularly problematic in trauma due to the mechanism of injuries and some patients that are victims of inter personal violence.

Conclusion: Focus groups were initially considered for this study as it is used in several other qualitative ICF studies (285, 396, 591, 592). However, many of these studies were in chronic disease rather than trauma. Due to the nature of how some patients sustain their injuries

which could affect confidentiality; the wide mixture of injuries sustained and the large geographical area from which to recruit patients, focus groups were discounted.

Unstructured interviews

Use: These are carried out face to face and can be topic or event based. The aim is to complete interviews and facilitate people to tell their own stories in greater depth and share experience. Interviews are recorded, transcribed and coded. Patient quotes are often used to highlight issues or experiences.

Advantages: Collecting peoples' opinion can provide rich data. It is more informal and the interviewer can clarify answers and probe the participant for more information. It is conversational in nature and the interviewer can be responsive to the participant.

Disadvantages: They are time consuming and expensive as the researcher may return to the same participant several times (372). Sample sizes are small which often leads to questionable representative data (116). Due to the depth of information provided it may be difficult to analyse and it could be difficult to determine when saturation is achieved. Participants do not have to reveal everything about them and resistance of participants may be possible (257). There is greater opportunity for interview bias due to the conversational nature and the interviewer requires a rich set of skills to listen carefully, probe, and adjust the flow of the conversation.

Conclusion: The aim of the research is not to gain an in-depth understanding of patient experience of a few patients, but rather to gain an overview of the range of problems of a large sample of patients. For this reason I did not use unstructured interviews.

Structured interviews

Use: This is normally used to ask a specific set of questions such as market research. It provides specific answers to specific questions.

Advantages: Answers can be analysed quantitatively to provide descriptive data on a specific issues for example, performance of a hospital which could be poor, average or good. This approach strives to obtain enough data to generalise outcomes or data to the general population.

Disadvantages: No depth or detail is obtained which is typically essential in qualitative research. It does not allow for hypothesis generation but rather confirms a hypothesis (372).

Conclusion: It is not the intention of the research to obtain answers to specific questions and this method was excluded.

Appendix 12: Payment by Results flow diagram (2013-14)